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ABSTRACT

Proceedings from a Special Studies Institute on the Challenge of Educating the Preschool Blind Child with Multiple Handicaps (New York, April 27-29, 1970) are compiled. Papers and panel discussion topics include the challenge of educating the multiply handicapped child with sensory defects; the physician's contribution in diagnosis, treatment and consultation; adapting professional knowledge and skill to service; educational techniques; problems of multiply handicapped children in rural areas; and the impact of Federal legislation on the education of the handicapped. (CD)

The University of the State of New York
The State Education Department

presents proceedings on

THE CHALLENGE OF EDUCATING THE PRE-SCHOOL BLIND CHILD WITH MULTIPLE HANDICAPS

April 27, 28 and 29, 1970

Division for Handicapped Children
Bureau for Physically Handicapped Children
in Cooperation with
Board of Education of the City of New York, Bureau for Visually Handicapped and
The Industrial Home for the Blind, Brooklyn, New York

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THE UNIVERSITY OF THE STATE OF NEW YORK

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This Institute was made possible by the United States Office of Education and the New York State Education Department, Division of Handicapped Children, Bureau for Physically Handicapped. In suggesting the subject for the Institute, the State Education Department responded to the growing professional concern for the education of multiple handicapped blind children. Dr. Anthony Pelone was invaluable in his guidance and help in planning.

We are indebted, also, to the panel members whose papers reflect a heavy investment of time and effort by professional people who are all extremely busy in their own work. Beyond the prepared papers, however, we particularly wish to acknowledge the cooperation of Mrs. Ferne Root Roberts, Director, Teaching Resource Center, City University of New York; Mr. Jerry Allford, C.S.W., Chief Psychiatric Social Worker, Psychiatric Clinic, The Jewish Guild for the Blind; Mr. Roger C. Walker, Principal, The New York Institute for the Education of the Blind; Mr. John San Fratello, Associate in Education of Visually Handicapped, Bureau for Physically Handicapped Children, who so very ably chaired the Institute sessions.

The proceedings cannot give the very rich and exciting experience of the second day of the Institute. Each participant visited two special education programs in the New York area, choosing one of the following combinations:

New York Institute for the Education of the Blind
Program for Multi-Handicapped Children
and
St. Joseph's School for the Deaf
Infant Training Program

New York University-Bellevue Rubella Unit
and
New York Association for the Blind
Child Development Center

New York City Board of Education Class
in cooperation with
The Industrial Home for the Blind
and
Willowbrook State School for the Mentally Retarded
Infant Educational Program

We wish to express most sincere gratitude to directors and staff of each of these organizations who so generously welcomed participants and shared the richness of their programs with all who attended.

/ A special acknowledgment must go to the gracious and creative members of the Planning Committee. Their willingness to give time to create a plan for a successful Institute and their help in selecting outstanding speakers was a major contribution to its success.

Elizabeth Maloney, C.S.W.
Institute Director

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A Special Study Institute

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INTRODUCTION

At the outset I want to express deep appreciation to Betty Maloney, the Director of this Institute, who I know has given considerable time and effort in planning and organizing this three-day Institute. My appreciation goes also to representatives from the New York City Board of Education, the representatives of the agencies for the blind and to those of you representing other public and private agencies working with the blind. My appreciation goes also to John SanFratello, the member of my staff who has been working at the Albany end in helping to plan the conference.

As we get under way for these three days we should derive encouragement from a number of developments that have taken place in recent years.

1. Never before in our history have we had the financial resources presently available to attack the barriers of the past in providing assistance for the handicapped.
2. Another is the concern of all segments of our society about the handicapped and I do not believe it has ever reached the present high level. This concern is diffused among government at all levels, all of the major disciplines such as medicine, psychiatry, psychology, social work and education, as well as the public.
3. We now have legislation at the State level which enables private schools to operate programs for the handicapped with State subsidy, thus assuring practically all handicapped children in New York State an opportunity of some type of school placement either in a public school or in a private school.

We have seen a sizable increase and interest throughout the country that the schools should have responsibility down to the pre-school level; that is, to include nursery school programs as part of the school's total responsibility. The Board of Regents of this State have taken a position calling for this and State funds are presently being used to finance experimental programs for pre-school children. Federal legislation has been passed and funds are now available to subsidize pre-school programs through the Handicapped Children's Early Education Assistance Act (P.L. 90-536). And of course we have had programs for many years in New York State for certain pre-school handicapped children including those operated in our schools for the deaf and the blind, by the New York City Board of Education, as well as a variety of programs and services sponsored by private schools and funded under the Family Court Act.

Our concern during these three days is about a group of children who present a real challenge to all of us in spite of the resources at our disposal. Why are we here? Certainly we want to press for a pattern of service that will break down further those barriers confronting these children so that we might help them reach levels of readiness to enter a school program at age five, not necessarily the usual structured program we traditionally think of, but rather a program in terms of the unique needs of these children. Certainly we are here to learn from one another. As I look at the program I see the names of persons who have already had a high degree of involvement with blind children with multiple handicaps. They bring to us a certain degree of sophistication and expertise which will benefit those of us who are expected to work with these children on a day to day basis. Thus, we already have a body of knowledge about this overall problem. We have more long-range planning going on. There is a greater degree of coordination in planning among the public and private agencies working on this problem. With the enlightened attitudes of many more school personnel, I would hope that what we do here this week will have as one of its major outcomes the acceptance of these children in school programs when they reach school age.

A few short years ago these multi-handicapped blind children were rejected by the schools primarily because the schools had neither the understanding nor the resources to deal with the challenge presented to them. However, because of the major involvement of our area agencies for the blind, our own New York Institute for the Education of the Blind and the New York City Board of Education and other agencies, attitudes about the eligibility of these children to attend school have changed considerably. Thank goodness for this because as all of you know even better than I, parents today are more sophisticated. As a matter of right, they expect the schools to provide a program for these children who have rather special needs. The evidence is clear that we are satisfying many more of these needs than formerly. Many children in school today were routinely turned away as recently as five years ago. A number still are. Many children in schools today are the children I referred to earlier to whom the routine response formerly was, "Well, I'm sorry but your child does not fit our program." More and more we realize that programs must fit the needs of the children who do apply. This is not to say that all children are accepted. But, Section 4407 of the Education Law does enable us to subsidize education in private schools if public school programs are not available, and we are finding placement possible in some private schools when the public school cannot meet the need.

Your speakers this morning have already developed a body of knowledge they can share with you so that as you go back to your programs the competences and skills you already have will be broadened in scope, there will be deeper understanding and, through the proceedings of this Institute, you will be able to disseminate throughout the State the new information, the techniques, that some of us will pick up here this week.

I want to make another observation concerning the program content. The consultants and participants represent for the most part the fields of medicine, education and social work. Obviously, we realize that you cannot plan a program, particularly for these children about whom we are all concerned, unless you have all three of these disciplines involved.

Any overall planning must merge all three services. Omit one, and you have no program. We well realize that the social factor, particularly in reference to environment, is paramount especially when you deal with the needs of children residing in New York City and other urban areas.

In closing I want to record the dedication of many persons in this audience. I know many of you are providing guidance and counsel to the families involved and services for their multi-handicapped children. I see considerable evidence of this through copies of correspondence which reach my office, through the membership of delegations who meet with legislators in Albany seeking legislative changes to strengthen services for these children, and through the zeal exhibited when called upon to plan and organize an Institute such as this. On behalf of myself and my staff, I wish to express grateful appreciation to all of you who have worked with Betty Maloney on this Institute. It is my fond hope that we will all benefit from the proceedings because these are the dividends we are seeking to help the children we are expected to serve. Best wishes for a most successful Institute.

Anthony J. Pelone, Ed.D.
Director, Division for
Handicapped Children

The Challenge of Educating the Multi-Handicapped Child with Sensory Defects

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Recently two teacher counselors who serve visually handicapped children on an itinerant basis in our county met with a group of graduate students. Two disconcerting observations emerged from the discussion following their description of the children on their case loads. First, the multiplicity and complexity of the problems were overwhelming. One child was being served by three professionals in addition to the teacher counselor for the visually handicapped: the school social worker, the speech and hearing teacher, and the consultant for the mentally handicapped. Ironically, the regular teacher seemed to be the most successful in helping him, probably because she was the only one to see him as a whole. This child was not unique and for most of the others the visual handicap, though severe, was minor compared with their other needs. A professional consultant would have difficulty knowing where to begin in order to offer these teachers meaningful and constructive help.

The second observation is perhaps more disturbing. In at least two instances, parents and child had had access to the broad range of services normally viewed as essential in problem prevention; and as adolescents, their adjustment was far from normal. At least two questions arise from this observation: what would these adolescents be like had they and their parents not had the help during their early years and, secondly, could their current problems have been anticipated and prevented if a different approach had been employed by the agency. The former question must remain unanswered because the clock cannot be turned back to follow a different path. Some consideration of the latter, however, may help to focus attention on program needs and evaluation of services that may lead to helping the handicapped make a better adjustment in adult society.

It is relatively easy for us to agree on what constitutes a complete program of services for the child with any single handicap. There would be general agreement on the need for early identification or case finding as well as early identification of his problems through differential diagnostic procedures; the provision of a continuum of services to meet his and his parent's needs beginning on the day he is identified; and an on going evaluation of both the child and the program. As professionals working with the child with a single handicap we do not fail in knowing what is needed, that we recognize readily; but often we do fail in implementing what we know, and more often that not our failure may be attributed to lack of adequate facilities, shortage of professional personnel, or similar reasons rather than to a lack of knowledge.

However, in providing services for the multiply handicapped, we fail because we do not know the <u>what</u>, <u>who</u>, and <u>how</u> of a complete service program. Case finding and identification of needs are complicated; the complexity and multiplicity of the problems make appropriate plans for remediation difficult since the best method for dealing with them is often not known and it becomes a challenge to identify and to secure appropriate services; under the categorical approach for providing services, no one wants to assume responsibility; and finally, the multiple impairments are treated as the sum of the disabilities whereas the interaction of one disability on the other or others creates a unique set of problems making the whole greater than and different from the sum of the parts.

A consideration of the elements in a complete service program as outlined above may help focus attention on what is known and not known; what is currently done and what remains to be done in program planning for the multiply handicapped.

Identification

Identification has a two fold aspect; first, case finding of the population to be served, and secondly, the diagnosis of the problems and needs of individuals in that population.

Case Finding

Early identification of the population to be served becomes critical when we see the results of not doing so. Any professional worker with any handicapped group can document this statement. For a population with more than one disability early identification is even more essential. School age, even nursery school age, may be too late. The day that a parent discovers his child is handicapped is the day when services must be offered. Educators and social workers have long recognized the necessity for giving help at this critical time. However, in many instances, appropriate referrals to these professionals are not made until much later when the seeds of an unsatisfactory adjustment are already sown. Studies of emotional adjustment of all disability groups emphasize the importance of early parent-child relationships.

Further, it is easy to initiate a cycle of negative reinforcement as early as the first few weeks of life that will be difficult to break later through even the most sophisticated remedial techniques. Parents, being people, have needs which must be satisfied. When a handicapped child does not respond to parental overtures, such as a smile, the mother may unconsciously interpret the behavior of the infant as a form of rejection of her; she in turn responds to this real or imagined rejection again on an unconscious level, and a cycle of negative reinforcement may be initiated. The hesitancy which many parents feel in dealing with their child because of their own attitudes toward disability especially toward the visual impairment may further intensify this vicious cycle. Early work with parents, then, becomes an essential element in prevention of future emotional problems and retarding influences.

Early case finding is largely dependent on the visibility of the impairment. Gross physical anomalies and severe visual loss tend to be identified before hearing impairments, mild visual impairments, emotional disturbances, and mental retardation. Furthermore, when a visible impairment such as blindness is found, there is a tendency to attribute all behavioral differences to it when in reality the differences may arise from an unseen, undiagnosed impairment. There are inherent dangers in this situation; either the undetected impairment may go untreated while vision is thought to be the basic problem or the developmental lag which may result from the deprivation caused by the visual loss may be wrongly diagnosed and the child labeled to his ultimate disadvantage. With multiple impairments there is a need to distinguish between those disabilities which are derived from the original handicap and those which are independent of it. The former, that is those which result from the original handicap, are probably more effectively approached on the preventive level; while the latter, those which are independent, are more difficult to deal with and must be approached through remedial procedures designed for that impairment.

While we may recognize the need for early case finding, developing a mechanism to do so is more challenging. Educators frequently do not know about a handicapped child until he reaches school age. In communities where there is a nursery school or preschool program, a child may be identified as early as three years of age. However, this tends to be the exception rather than the rule and, in addition, three may be too late, particularly in the light of research findings on the disadvantaged (Bloom, 1964).

Early case finding should be initiated by the profession or discipline which is most likely to see the child first. Since a visual impairment is a medical problem, this initial professional is usually the pediatrician and/or the ophthalmologist. In our highly specialized and often fragmented professional settings, the need for identification and utilization of supplementary resources is often not recognized. It becomes necessary then that the medical profession, including public health nursing, the social agencies, both general and specialized, and the school, work together in a team relationship in order to provide the communication network that is essential to achieve the objective of early case finding and to secure appropriate services for the handicapped infant and his parents when they need them. The lines of communication among these disciplines must be open and a team working relationship must be established for the duration of the service program.

Any attempt to determine which discipline is responsible for initiating referrals becomes complicated because of variations in available types of services offered in different communities. Professional workers within any one community must develop the most appropriate mechanism for that community. In one, it may be the public health nurse; in another, the public schools; in yet another, a social agency, either general or specialized. The delineation of who is responsible should be made on the basis of existing resources within the community. However, communication and cooperation of all concerned will be necessary to implement an effective mechanism.

The practices followed in England, as well as other European countries, may be illustrative of a workable mechanism. In England a child born to a mother with a history of illness during pregnancy, prolonged labor, or difficult delivery is identified as potentially handicapped and is placed on a high-risk registry. A nurse visits the mother when she returns from the hospital, and at frequent intervals during the child's early life. At each visit the child is examined, carefully observed and is referred to a physician when there is even a remote suspicion of a defect. In such a setting, early case finding can take place and appropriate remedial measures initiated. It may be possible in some communities to adopt a similar program through the cooperative efforts and communication of all disciplines concerned.

Differential Diagnosis

The importance of the second aspect of identification, namely, the differential diagnosis of the special needs of both the parent and child, is likewise well known and recognized. As professionals, we know that parents need on-going supportive services in order to cope with the problems they are encountering at each stage of development in rearing their handicapped child. In order to evaluate problems, professionals must know the potential impact of each impairment on the process of growth and development. In general, variations observed in the growth and development of handicapped children compared with normal children are usually variations in the rate of growth that result from direct or indirect influences of the impairment. Direct influences impose limitations or restrictions on the child for which he must receive compensatory experiences; indirect influences are those that are culturally or environmentally determined and are alleviated by programs directed toward modifying forces outside the child himself. The first group of influences are primarily the concern of the medical profession; the latter, the responsibility of the social scientist working in the helping professions.

Two general characteristics of growth and development for all children should be noted: the sequential nature of growth and the tendency of the organism to maintain its equilibrium. That growth is sequential means that there are certain identifiable stages through which all children pass and knowledge and understanding of these stages becomes important for parents and teachers of multiply handicapped children. Enriched experiences at the appropriate time may often be provided within the environment in order to compensate for deficiencies resulting from the impairments.

The tendency of an organism to maintain its stability is likewise important. While there may be periods of regression, particularly in emotional development, these periods are usually temporary and transitory and should be expected as a normal part of the total growth and developmental process. Brief plateaus and even periods of regression should not be cause for concern on the part of parents. Professionals may need to provide supportive services to parents to avoid their feelings of discouragement when no progress seems to be occurring. They may be comforted by the assurance that a rapid spurt will often follow the quiescent period. Within the scope of this paper, it is not possible to detail all the special needs during the developmental process of the child with multiple handicaps. We will, however, attempt to highlight briefly certain of those which are of special importance to professionals working with the visually handicapped child who has other disabilities. More details may be found in Fraiberg, et al-1969, Halliday-1970, Lowenfeld-1969, Scholl-1970.

The various aspects of growth and development are often divided into the following areas: physical, mental, emotional and social. While the interrelated nature of growth and development makes such a division artificial, it is perhaps useful.

In physical and motor development, a visual impairment in and of itself probably does not retard the child's progress as, for example, cerebral palsy does. However, there are some indirect or environmental influences that may and often do retard development. A lack of opportunity because of parental overprotection and misunderstanding of needs may deprive the child of opportunities to learn to use muscles that are necessary in order to acquire certain physical skills. Additionally, because he lacks the opportunity to learn through imitation, the child may not acquire certain physical skills unless a conscious effort is made to teach him. Finally, the limitations of the impairment in the ability to get around and to control his environment may effect optimal growth and development. Providing adequate stimulation for the development of physical and motor skills presents a challenge to the teacher or other professional working with the parent.

Retardation in learning fine muscle coordination is often observed in young handicapped children. Experiences with activities that are directed toward improving hand and finger coordination are necessary in order to compensate for this deficiency. Kindergarten may be too late to initiate intervention, and hence, it is essential that early work with parents to help them provide the necessary intervention should be an integral part of the educational process.

Orientation to one's environment and the development of mobility skills begins while the infant is still in his crib. Sensory stimulation through channels other than vision helps make the world outside the child more interesting. However, sensory stimulation must be structured and must be meaningful. Where possible, objects should be attached to the sounds they make; constant playing of radio or T.V. should be avoided. Unless meaning or significance is attached to a stimulus, it will tend to be ignored (Kagan, 1962). Therefore, the environment should be structured with stimuli that are meaningful and can be utilized by the child to learn about his world.

The knowledge of how one's body moves in space helps the child orient himself in relationship to his environment. Activities such as movement education, play which provides an outlet for expanding physical energy, and opportunities to develop fine muscle coordination must be provided by parents early in the child's life so that good body coordination and the ability to get around easily and efficiently may become the base on which specific mobility skills and techniques may be developed later.

Another need for the handicapped child is early training in the skills of daily living. Feeding and toilet training should present no great difficulty provided a few guidelines are followed. For both, a state of readiness or set must be established. This can be accomplished through verbal and non-verbal (in the case of the child who is also deaf) communication between parent and child that will make the experience pleasant and one that the child anticipates eagerly. New objects in the environment and new experiences must be introduced slowly with plenty of opportunity to explore through other sensory avenues. Dressing should likewise be a normal process provided the child has an opportunity to explore his clothing by touch, learns on what part of his body each belongs, experiments with both taking off and putting on each item of clothing, and finally masters dressing himself. His progress in this area should approximate that for a normal child if parents are patient and help facilitiate the learning process. Habits of good grooming are formed in the preschool period and parents should help the child develop an ability to see himself as others see him through verbal contacts since he lacks the stimulation and motivation for acquiring such skills through the mirror play of the normal child.

The interrelationship of emotional, social and personality development makes it difficult to separate these aspects. The ultimate objectives in this area are socialization, meeting affective needs, the development of the self-concept, and becoming independent. Any influences of the visual impairment on development in these areas are primarily indirect or environmental.

Socialization for the normal child begins with the formation of his relationship with his mother. This process is initiated soon after birth when the mother holds the child for the first time. As he grows older, eye contact stimulates the development of a relationship first with his mother and later with the other members of his family. For the visually handicapped infant, relationships are formed through his other senses: the sound of voices, and the touch and pressure of the mother's body on his.

The infant gradually expands his relationship with his parents to include his other family members, particularly his siblings. One caution should be noted when working with parents of the handicapped child to insure that the dependency of the child does not become a burden on his siblings. The right of normal siblings to engage in activities with their peers should be respected and all should be treated fairly and justly with no special consideration granted the handicapped child because of his disability alone.

From the security gained through meaningful relationships within the family group, the child moves to others outside the family. Again, the handicapped child is at a disadvantage as he enlarges his circle of relevant others. Visual contacts help the preschool child know when he is acceptable in his peer group. The visual impairment deprives the child of the opportunity to initiate contacts and to know if and when he is accepted and acceptable. Parents may need to help the child demonstrate abilities and activities planned by the family should include peers in order to help assist in bridging the gap between the security of the home and the unknown world outside the home. Often parents need to engage in more structured teaching of certain skills and acceptable modes of dress and behavior because the child cannot learn such things unconsciously and by imitation.

Learning to love and be loved begins in infancy. Parents and teachers of very young handicapped children often need to provide more physical contact than is necessary for normal children since physical contact must often take the place of sensory contacts. There seems to be a greater need for being close to an adult. This may be a reflection of the desire to obtain security and acceptance that the normal child receives from his intact senses.

Research on the self-concept identifies the importance of a healthy perception of the self relative to physical and social environment for achievement, not only in school but in later life as well. For the child who is deprived of sight, the object world is known only through the sense of touch. The body image normally acquired through visual observation and mirror play becomes real to the blind child through tactile exploration and later through verbal communication and feedback when language becomes meaningful. However, these avenues are inferior in providing information concerning his body compared to the bodies of others. A body deformed by a physical impairment places an additional barrier on the development of the self-concept.

The more limited number of peers and peer group experiences further retards the handicapped child. Parents often attempt to protect him from negative feedback and this overprotection may contribute to developing an unrealistic view of himself. While in general, success experiences are necessary, failure may provide the ingredient for developing a realistic self-concept.

One objective in the maturation process is to become independent. While total independence in all areas is neither a desirable nor an attainable goal, everyone does need to learn when to rely on one or more persons for satisfactory gratification of needs. The period of dependence may be unduly prolonged in the handicapped child and his ultimate degree of independence may be less than that for the normal child. Therefore, it is important in working with handicapped children to help them know under what circumstances independence is a desirable goal and when dependence must be accepted. Parents and teachers must be aware of the child's readiness and need to assume more independence at each stage of his life. It may be necessary to provide stimulation at the critical times in order to insure the learning of a particular skill at the appropriate age. Parents need to be aware of the fine line between expecting too much and not expecting enough.

Any sensory impairment has a handicapping effect on mental development. While certain concepts cannot be expected of the visually or auditorially handicapped child, it would appear that maximizing other sensory experiences may help compensate in part for the deprivation. Bloom (1964) postulates that an enriched environment will be most effective when characteristics and behavior are in their most rapid period of growth. He says that as much development in intelligence occurs during the first four years of life as in the next thirteen years. It is essential, therefore, that the child with sensory deficits be provided with optimal experiences that will give as rich a background as possible so he may develop as near normal as his limited capacities permit. Sensory stimulation that does not have a meaningful base may result in later ignoring relevant stimuli. The child is unable to sort out that which is meaningful and he may block out all stimuli thereby giving the appearance of withdrawing and not paying attention. In working with parents stress should be placed on introducing new sensory experiences in a setting where there is meaning or significance, otherwise the child may slip into his own world where no response is expected or necessary. In addition, direct efforts should be made to help the child make maximum utilization of his remaining sensory functions, no matter how restricted they may be. All available sensory cues should be utilized in order to make up for deficiencies caused by the sensory impairment or impairments.

The breadth of concept development is dependent to a large extent on the breadth of the perceptual experiences. Because the handicapped child lacks one or more sources of sensory input, his perceptual processes will be more limited. He may never grasp some concepts and may need more experience than the normal child to grasp others. Parents need to be aware of potential difficulties in the area of concept fomration and in particularl they should emphasize meaningful concrete experiences in order to maximize concept development.

Speech and language are essential elements in the process of oral and written communication. In general, the visually handicapped child acquires speech and language through imitation the same as the normal child. However, if he is slow in his physical development, he will probably also be slow in this area. The number of words acquired during the early years may be fewer because the lack of visual stimulation results in a slower rate of vocabulary acquisition. The child who has a hearing impairment needs specialized help to acquire communication skills.

It is probably difficult for us who have intact sources of sensory input to understand and appreciate the profound isolation of the child who is deprived of vision and/or hearing. Direct intervention is essential to reduce the impact on later development.

Program Planning

Variations in kind and degree of impairments make it difficult to generalize about appropriate remedial measures or services that are necessary to meet the developmental needs of multi-handicapped children. However, we may identify some guidelines that will be useful for program planning.

1. The need for a meaningful and realistic diagnosis from qualified professionals: the medical specialist, the psychologist, the social worker, the educator, working together as a team to formulate a plan that includes both long-term and short-term goals.

We have a great tendency in writing reports to tell the referring person, whether this be agency or parent, what he already knows and why he made the referral in the first place. If reports do not contain information relevant and meaningful for educational planning, then the referring person should make an additional specific request.

There is a further caution regarding evaluation whether this be medical, psychological and/or educational. The behavior, particularly of a child with multiple impairments, may be wrongly judged because of a deprived experiential background. For example, a blind child cannot be expected to recognize and know the purpose of even a common household tool, such as a spoon, if he has never been permitted to explore such an object while it is being used. Additionally, behavior of any type must be evaluated against the background of the known and/or possible characteristics in his environment. Sensory and experiential deprivation can cause behavior which may appear abnormal but which is quite normal considering abilities and environmental opportunities. With the many possible combinations of handicaps which may be present in the multi-handicapped population, "normal" behavior can be adequately evaluated only by knowing as much as possible about the kind of experiences and stimulation the environment has provided.

Finally, to be useful for program planning, the assessment should include a description of capacities and abilities as well as the limitations.

2. Understanding and helping parents. Every professional who has worked with parents of handicapped children will admit (after some soul-searching) that he has made one or more mistakes that he would rather forget. Most of our mistakes result from our lack of real understanding and empathy and our tendency to condemn too quickly. How can anyone except the parents, really understand the pride in simple accomplishments that are sometimes degraded by the professional; the frustration of meeting little or no response for twenty-four hours a day, month after month, from a multi-handicapped child while the professional says during a brief visit that more should be done; or the fear of what will ultimately happen to this child and who will care for him when they are gone. How can we truly understand and help the family unless we respect and admire the parents for what they are able to accomplish, little though that may seem to us. We make many demands on parents, sometimes more than they are able to accept. A guiding principle in working with parents is to try to be understanding and to give support that will help them face the many problems of child-rearing and to help them find answers to the problems.

3. Use of Imagination and Creativity in Program Planning. We must be creative in identifying ways to help parents through their problems but most of all to help parents to be creative in solving their own problems and to see themselves through. There is a fine line that needs to be recognized between giving too much service and not giving enough. For most parents, visits of the professional worker at six to eight week intervals are far from adequate. Parents need help with specific problems at the particular time when problems arise. They also need to understand the "why" of a particular recommendation. If, for example, the professional can demonstrate to parents through simple techniques of blindfolds and ear plugs, the profound isolation that results when these avenues

of sensory input are missing, they may understand somewhat better the need for meaningful sensory stimulation for their child and will be more creative in providing such stimulation. Playing with kitchen pots and pans, fitting measuring cups or spoons of different sizes into each other, building with various size boxes and cans, may be of greater value in giving the child an understanding of objects in his environment than the most expensive educational toys. Similarly, lacing his father's shoes or working on the many different latches and locks found in the home may teach necessary skills for functioning in his environment better than elaborate commercial boards from which one hopes transfer will occur to the real situation. Even the most deprived home includes objects that can be used as educational toys and they are less expensive and may be of greater educational value.

4. Selection of the appropriate educational experiences outside the home based on each child's needs. During the pre-school years we tend to think of nursery school as the answer to meeting every child's needs. Programs in nursery schools vary in emphasis, structure, and kind of children served. A regular nursery school may not provide sufficient stimulation for some and may not be appropriate for others. Even the best regular nursery school teacher may require special help and guidance when a handicapped child is enrolled. A highly structured program may work well with some children and not at all for others. The important task for the professional is to select the best and most appropriate program based on a study of the child's needs. However, sometimes even a poor nursery school program may be justified in order to give the mother some relief from having the child, thus affording her an opportunity to re-charge her batteries. Just because a particular nursery school experience was good for one handicapped child does not necessarily mean it is good for every handicapped child.

5. Deciding which disability is most important to remediate. The multi-handicapped child presents a never-ending challenge to determine which disability takes precedence for program planning. Furthermore, such a decision cannot be made for all time because needs change during the developmental process and as needs change, remedial programs must also change. Any one disability may be more or less handicapping at particular stages and under different circumstances. Only a program that includes on-going evaluation and assessment throughout his life can meet these varying needs.

6. Maximizing the team approach. The needs of the multi-handicapped child can be met neither by a rigid adherence to the categorical system in special education nor by any one discipline. Working as a member of a team is not easy, because most of us are individualistic and often think we can do a job alone. If services for the multiply handicapped child are designed to meet all his needs, then special educators of all categories and

professionals from all disciplines must abandon their primadonna image in favor of the team approach. Further, professionals must learn to utilize the potential contribution of para-professionals to the team and learn to work with them. Finally, parents must be included as members of the team because in their role, they have a vested interest in what happens to their child and thus should be included in program planning.

7. Assume there is another potentially handicapping condition. Professionals working with any handicapped group are aware of other disabilities of varying degrees and kind in almost all their students or clients. In some instances, such as mental retardation or emotional disturbance, it is difficult to determine whether it is inherent in the visual problem or independent of it. This differential diagnosis could probably be made only at a very early point in the child's life. Thus, with the possibility that there may be another disability, professionals working with any single category should assume the likelihood of that possibility and should take steps to identify and remediate the condition as early as possible or, ideally, to develop a continuum of services that will prevent the development of another handicap. There should, however, be a note of caution, namely, to avoid early labeling with all its potential dangers.

Evaluation

Evaluation has a two-fold aspect. Continuous evaluation of needs of the child and his parents must be recognized if the program of services is to be adequate. This aspect is more likely to be accomplished than the second side of evaluation, namely, on-going and continuous self-study and evaluation of programs. It is probably safe to say that very few schools or agencies are concerned with the evaluation of their product once he leaves or is no longer eligible for services. However, if programs are to be improved, evaluation through continuous follow-up must be an important element and an accepted part of program planning. Improved services result when the program does include continuous and on-going evaluation and when staff members are willing to engage in a program of self-study honestly and openly.

Conclusion

Wright (1960) distinguishes between "impairment" or "disability" and "handicap." The distinction is further refined in the Rehabilitation Codes (Riviere, 1964). In the latter, impairment is a condition that can be objectively defined in medical or para-medical terms; disability is the restriction which the impairment imposes upon the individual's functioning when compared to others of similar age, sex, or cultural background; handicap is the restriction which society or the individual himself places upon himself because of his impairment. Those of us in the social sciences, social workers, and educators, can do little to alleviate the effects of impairments and disabilities; this is the role of the medical specialists, technologists, and other related scientists. However, we can do much to minimize the handicaps.

On a theoretical or philosophical level, there should be no handicaps resulting from impairments or disabilities. The impaired individual should be exposed to such an ideal environment that neither he nor society would or could impose restrictions on his functioning. Unfortunately, this is not the case; and we professionals sometimes unwittingly contribute to the development of handicaps through ignorance, through naivety, or worse, through a refusal to identify the problem accurately and work together to provide a complete service program for the impaired. The efforts of every service program for the multiply handicapped should be directed toward reducing the degree and kind of handicaps so that they may lead as near normal lives as possible. With this as an ultimate though probably an unrealizable objective, programs can and will be more effective.

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The Physician's Contribution in Diagnosis, Treatment, and Consultation

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To save time, I will not refer to those aspects in the management of the child with multiple handicaps which have already been covered, although what has been said should be correlated with this medical presentation.

What is a multiple-handicapped child? I shall talk about the individual parts which compose a multi-handicapped child, with sensory disturbance. Actually, the child isn't fragmented that way. Medically, a youngster is labelled as a specific type, according to the part of his handicap which happens to be predominant. I do not believe, for example, there are many mentally retarded children who are not disturbed organically. It is essentially an organic handicap. It is all right to talk about cultural or familial amentia, but on examining the child one finds a lot of difficulties present. It becomes obvious that this is not a pure case of lack of adaptability to environment, on a scale which we call normal or in this case a little below normal, but rather that there are difficulties which the normal child, so called, does not have.

I am a pediatric neurologist in a school for autistic and schizophrenic children. The Director asked me to come there, because he felt there was a good deal of organicity present in the pathology of these children. All one has to do is to watch a class of autistic children in a gym; watch them throw a ball or hop, skip and jump -- watch them write, and one picks up innumerable handicaps in coordination and function. Though I may stress individual items, remember that these handicaps are all composites of a general picture.

Certain features are essential to the multi-handicapped. Most common among these are neuromuscular:

CEREBRAL PALSY

Cerebral means brain; palsy means a limitation of movement so that these children have neuro-motor disturbances on the basis of brain pathology. Poliomyelitis, as a contrast, would be a limitation of movement on the basis of spinal cord pathology--not involved with the brain. We are essentially looking at those disabilities that have to do with brain impairment.

1. Spastic - The majority of cerebral palsied children are referred to as spastic. The spastic child is simply a youngster whose muscles, on movement, get tight. He may attempt to bring a spoon to his mouth or take a step, or to talk. However, as he attempts to do so, his muscles tighten, so that instead of being able to bend his elbow, for example,

there is no relaxation and he is unable to carry out his movement.

2. Athetoid - Together with the spastic, these two comprise a majority of children with cerebral palsy, 65% spastic; 15 to 25% athetoid. In athetosis, the movement is bizarre, uncontrolled, involving distal portions, hands and feet, which go through a sort of sinuous movement with marked amplitude. There are also facial grimaces, and the tongue wobbles in all directions because there is a complete lack of control in all movement.

3. Ataxic - In these children, there are problems of incoordination of movement and speech. The child walks with a broad-based gait because he must feel his way along, since he does not receive normal impulses through the spinal cord to the brain to tell him he is walking safely; he must move with care.

4. Rigidity - The rigid child is a more involved youngster than the spastic. The spastic child, when at rest is relaxed, while the rigid child is in a constant state of stiffness. This is called leadpipe rigidity. If raised by the neck the whole body will come up as one piece. This is usually associated with very severely retarded mental development.

5. Tremors - These are to and fro movements of the extremities.

6. Hypotonic - In contradistinction to the spastic whose tone is increased, muscle tone is diminished, the child is floppy, flabby. This is a rare form of cerebral palsy which has to be distinguished diagnostically from other muscular weaknesses such as from the amyotonic group and the muscular dystrophies.

If cerebral palsy were nothing more than the combination of various forms of neuro-motor disability, the problem would be severe enough but, unfortunately, the cerebral palsied child is a multi-handicapped child. Almost every cerebral palsied child has speech difficulty.

Movement arises by virtue of the fact that we receive sensory stimuli through the skin, eyes and ears - impulses are transduced into the motor area and we have movement. Problems in speech are related, because impulses must pass down through the brain stem, the lower part of the brain where the vital nuclei for existence are present, on their way to our tongue, palate, pharynx, which are involved with speech.

In the athetoid, there is a further difficulty in that breathing takes place at one level and speech at another level, and there is no coordination between breathing, diaphragmatic movements and the [illegible] of the palate, pharynx and tongue. The ataxic, because of incoordinated movements of tongue and palate, also has problems in speech.

In addition, there are visual problems. Two of these are specific to cerebral palsy. One is the lack of version, which means that as I look directly at you I am also able to see the ceiling, the floor, and the two side walls because I can move to either direction with my eyes. These youngsters are limited in version -- they are limited in supraversion and in lateral version. The effects of this are obvious. If the child has limited version and the teacher is at one end of the black-board and the child cannot veer to that direction, he is not getting what he should out of the lesson. Strabismus, paralysis of the eye muscles, is also common.

Auditory difficulties are present and are primarily in the child with RH problems or in any youngster who in the newborn period develops a severe degree of jaundice, irrespective of cause. This may produce destruction of the peripheral end portion of hearing called the cochlear region, or it may involve the receptive auditory region in the temporal lobe, so that a child with an RH problem may have either type or both.

About 15 out of every 100 cerebral palsied children will have seizures, which must be treated with Phenobarbital or Dilantin sodium if seizures are major. If seizures are of a minor type, such as momentary lapses into space, which may happen 20-30 times a day; or akinetic seizures, where the head may drop to the chest or the child may fall to the floor, they must be treated with other drugs such as Zerontin.

Finally, the emotional effects in cerebral palsy are tremendous. As has already been described by the previous speaker, here is a youngster who does not have the normal development or the experiences of the average child in walking to various places, he is limited motorically. The average child is quite independent in his second and third year - everything in the second year is no, no, no - he wants to get away from the parent and do things for himself. Here we have children at seven who have to be fed, to be helped with dressing, toileting, zipping, cannot handle normal activities of daily living without help. Further emotional difficulties result from two sources --

1. The parents have tremendous guilt about having produced such a child.
2. Child is annoyed by constant dependence on parents, and parents, in turn, are annoyed by the constant restrictions in their lives.

Treatment may be group therapy, psychiatric and psychological help, to try to offset these difficulties.

Etiology

Cerebral Palsy is not a name for a specific disease entity. If the name of a disease is know, term C.P. is not used, i.e., hydrocephalus with spastic quadriplegia (spasticity of all four extremities).

Among causes, prematurity is a major cause. Not only is it the cause of cerebral palsy, but children born prematurely are vulnerable to retarded mental development and to seizures. With the premature birth, the blood capillaries are not fully matured, the storage of glucose in the liver is not as great as it should be. After the child is born, he may be subject to a noxious environment; he needs his glucose and oxygen. His blood vessels may rupture more readily. The greatest vulnerability is in the areas of the brain related to the motor system, and it is those areas that have to do with the function we have talked about and, therefore, they become involved more readily. One other factor. There is enough experimental evidence to suggest very strongly that malnutrition occurring in the first months of life definitely reduces the number of ganglion cells or brain cells which should be available. In the development of the brain cell, first there is an increase in the number and, in the second trimester of pregnancy, the cell increases in size. So, if malnutrition occurs in the first trimester, particularly, the number of brain cells does not increase. Post-mortems show a paucity of cells and a lack of development of brain tissue into its component parts so that although we are accustomed to talking of malnutrition later in childhood, the damage may well begin early in the pregnancy.

Treatment

Therapy for children with cerebral palsy includes physical therapy to relax their muscles, occupational therapy to teach them the activities of daily living, speech and language therapy. There are also social workers to work with the parents and psychologists, both to do testing and work with the children and the parents. Therapy must involve the local educational system, in a liaison between the doctor and teacher, so that there can be a transfer to the educational system of the medical findings, a transfer which is so frequently missing in ordinary medical care. In an ideal plan, such as one that I suggested two years ago to a Congressional Committee, there would also be someone from the educational system assigned to working with the family in the home.

MINIMAL BRAIN DYSFUNCTION

Now let us talk about another problem which has been given a lot of attention -- the child with so-called minimal brain dysfunction. Many names have been used, e.g., organic brain damage, chronic brain syndrome, hyperkinetic child, etc. I would like to caution against the use of the term "brain injured." Many of these children are not brain injured and the term should not be applied to them. These children may, however, show symptoms similar to those of a child who is brain damaged. There may be no evidence in the course of the study of the prenatal period, or in subsequent developmental history, to suggest brain damage. What we need is some term that will indicate brain dysfunction, but will leave it to the physician to decide the existence or the degree of brain damage on the basis of evidence. On occasion, I see reports of psychological testing which show a discrepancy between verbal and performance function on the Wechsler Intelligence Scale for Children, leading to a conclusion of brain damage, and such conclusions leave me cold. All such reports can do is to suggest that there may be a possibility which should be looked into. There are emotionally disturbed children who may show all of the same findings, but in whom there is no evidence of any organicity. It is vital that we use extreme care in interpreting data that we collect, and for that reason let me say this now, in case I should wind up without another opportunity to say it: the crux of any study of a child should be to forget labels and instead to determine what are his assets and what are his deficits and to develop an educational plan which will enhance the assets and overcome the deficits.

The child with minimal brain dysfunction has two major symptoms: one, behavior characterized by being hyperkinetic, with a short attention span. The child is distractable and constantly on the go. Educationally, he has visual-motor and perceptual difficulties. Our job as doctors, once we have made a diagnosis, is to help the educational system by using drugs to help control the youngster. The favored drugs are the amphetamines such as Dexedrine, Methyphenidate (Ritalin). The average human being takes these drugs for stimulation, but with these children the effect, paradoxically, is the opposite. They do not work with every child and it is a matter of using one drug at a time, until the right drug and proper dose is found for the child. The drugs make the child more controllable so that he can concentrate on the work at hand.

MENTAL RETARDATION

In children with retarded mental development, it is important to look for problems of a neuro-motor nature and in the visual-motor areas. You cannot assume that the child merely has a broad overall area of deficiency in intelligence; he is the same as any other child; he has assets and deficits and we need to be sure of both in working with him. In the broad scale of intelligence measurement, when we get to the area of retardation, we find that the lower the I.Q. and the more severe the retardation, the more frequent are areas of associated difficulty. The reason for this is, that these are the children who may have had German measles or who have chromosomal aberrations or bio-chemical defects. These will show up in a multiplicity of systemic defects, because they have affected the child at the time when his organs were in the earlier stages of development (first trimester pregnancy). The child who has hearing defects on a genetic basis is more apt also to have visual defects because the hearing mechanism and the visual mechanism originate from the same area, embryologically, and develop at the same time.

AUTISM

Next, a brief discussion of the autistic child. With the autistic child the most outstanding characteristic is his failure to have any relationship to his environment and usually his failure to develop speech. It is essential that differential diagnosis be carried out to determine whether such a child is autistic, or whether there may be aphasia, mental retardation or sensory difficulty (deafness).

Now we will go on to another group. Thus far I have discussed brain functioning in relation to the neuro-motor area which is pre-frontal and the sensory area. In the remainder of the cortex there are the parietal, occipital, and temporal lobes. Each of these have specific functions. In the temporal lobe, auditory reception takes place. There is an analysis of what is heard and a coding of what is heard, and finally a storage of information. When there is disturbance in the temporal lobe one must determine, can the child hear, or is he deaf? If so, what are the limits of his hearing ability or disability? Does he have aphasia? Ten years ago I wrote a textbook of pediatric neurology in which I said that aphasic children have normal hearing and a normal I.Q. Since then, we have learned that aphasic children often also have partial hearing loss as well. Today, I can say that the child may have further problems translating auditory receptive symbols into visual symbols, and this is where one of the problems in education occurs. We also don't know how we transduce visual and auditory symbols into memory and conceptualization, and how they are coded. Until we do know more about these functions, our ability to educate children with difficulties in these areas will be limited. Finally, I would like to discuss the visual areas of the brain which occur primarily in the parietal and occipital areas. Pathology in these areas result in spacial deficiency. We cannot tell right from left; there is a failure of understanding in laterality; we have so-called dyslexia. We cannot recognize differences in shapes, so we do not differentiate between symbols. It is therefore obvious that the posterior part of the brain in contradistinction to the forepart of the brain has to do with our senses, sight, hearing, etc., whereas the forepart of the brain has to do with sensory motor and neuromotor activities.

As educators, it is important to look at the whole child to try to determine what are his abilities as well as his disabilities. Will he be better if he is visually taught? Will he be better if he is auditorially taught? Will he need to be taught through tactile and kinesthetic approaches? There are cerebral palsied children who need a back brace to keep their head from wobbling. There are others who learn to write on an electric typewriter using their feet.

Finally, as physicians, how can we serve as consultants? Much has already been said, very well, on this subject.

We must work on prevention. The RH problem will be wiped out in a few years as vaccination of mothers is developed. A Rubella vaccine has already been developed. Toxoplasmosis, which causes blindness in infants, is being studied through maternal research. We are recognizing that certain chromosomal disorders result in hearing and visual disabilities. Mongolism is another chromosomal disorder. Learning this means that we will be able to detect carriers and be able to avoid these handicaps. Apart from prevention we must search for early diagnosis and the doctor must be responsible for procuring total diagnostic studies including hearing and vision. After this is complete then he must work with the community, through the agencies and schools, both socially and educationally, to see what can be done for the child. Not only during the school years, but even in planning for adult life.

Psychological Evaluation of the Multiple Handicapped Preschool Blind Child

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For the next several moments I would like to give some of my impressions as an examiner of multiple handicapped blind children. The populations I have primarily been involved with have been the groups of children diagnosed as suffering the post-rubella syndrome and those suffering retrolental fibroplasia; more recently the former has been more numerous. Heretofore, there has not been the stress toward early screening of these children, screening for assessment of both deficit and asset with the view toward early exposure to preschool programs in order to capitalize on assets so as to permit exploitation of whatever stimuli can be incorporated and integrated, at the earliest possible time. With this philosophy comes the dilemma of the process of assessment, assessment perhaps even at an age before certain language and cognitive skills would develop in the ordinary child or in the regular course of developmental events. Thus, early assessment carries with it the predictive elements---will this particular child or infant have severe problems in acquiring the developmental stages necessary to perform associative and integrated tasks. This is especially useful to know with blind babies who will eventually be learning through avenues other than pure vision and thus the mechanisms of learning not altogether understood by either psychologists or educators. The two most important goals of early examination are: one, assessment of current level of development and, two, an attempt to very early hypothesize upon the modality or sensory area which appears to be the most disabling area as far as mental maturity or developmental status is concerned. This is, of course, most difficult under 12 months, before expressive language is spontaneously used to communicate. The older the child the more obvious the deviant area becomes. Unfortunately, however, the whole thesis of this discussion is that we should not wait until deficit is so obvious. For example, I can think of a child I examined on three different occasions, spanning a time of about 36 months in all, from age 15 months to approximately age four and several months. He was a child with post maternal rubella syndrome and had all the sensory symptoms including a hearing loss, visual deficiency, and some muscle weakness. This child began showing signs of serious language delay, receptive and expressive when first seen at 14 or 15 months of age; however, stress was put on the visual deficit by both the agency dealing with the youngster and the parents. By 2½ years of age this now obviously visually oriented toddler had no speech and seemed to comprehend very little despite ability to hear the spoken word. Parents were advised to seek the help of a language specialist and think about a nursery school program geared toward the education of the language impaired child. For reasons too complicated to reiterate, these parents were willing to accept a visually impaired youngster, but rejected the possibility of a visual impairment--he didn't speak simply because he couldn't see. Also, around 30 months it became obvious that the speech problem was related to brain pathology, as cognitive and associative learning was not taking place despite exposure to an individual pre-nursery program aimed at developing beginning associative concepts with legally blind and totally blind children. At this age it was obvious that this youngster used residual vision adequately, but could not interpret the visual stimuli received. By 52 months this youngster was still in a program primarily geared for the visually handicapped. Some automatic speech had developed, parents very proud of his ability to recall radio and T.V. commercials (which they reinforced by their pleasure) and even recall entire musical shows, complete with imitation of musical instruments. However, 80 percent of this boy's language was relatively meaningless because it was not applied to making more complicated mental associations in order to enhance the child's cognitive repetoire. By this stage it would now be necessary to inhibit language--the automatic, compulsive speech--in order to instate meaningful verbal concepts. The child had already been deprived of the "right start" for an individual with a language impairment, congenital in etiology and picked up at 14 months of age. By this time, also, the parents had been greatly encouraged by the advent of expressive language and it was virtually impossible to interpret the latest findings to them; they could not accept the concept of brain pathology, no matter how gently approached, still only seeing the son as visually limited and "late in talking" because of an initial hearing problem. His future school plans will probably include a Board of Education Class for Visually Limited Children, which still will not meet his needs as interpreted developmentally.

This rather unfortunate illustration, although by no means unique, was in way of bringing out the importance of very early assessment into the primary deficits of acquiring developmental skills, the primary deficits not necessarily being the most obvious ones, or even the deficits being studied or defined by the agency where the psychological consultation is being performed. Where the multiple handicapped child is concerned, no agency corners the market in rehabilitating him; it must be a cooperative effort either in an agency having consultants from a variety of disciplines or an effort between several agencies servicing the family.

In speaking of the tools of assessment one cannot rely upon available "kits" or packaged and standardized tests and psychometric measures. One can use those which apply, but again, one cannot rely upon them because they only tell us what the child cannot do, not why he cannot do it. Assessment should have a three-fold purpose: one, as a diagnostic device, in order to pinpoint as closely as possible reasons for some kind of failure or deviant samples of behavior. Two, we assess as a way of discovering how the mind works--what are the components and structure of intellect, for example. Or more specifically, why does a particular child fail a particular task--is it a problem of sensation, i.e., he does not see it; a problem in perception, i.e., he interprets it wrong; or a problem in expression, i.e., he sees it and interprets it but he cannot carry out the action he sees. A series of developmental tasks thus must be observed, using the normal sequence of maturation as the basis of the framework in order to assess where along this developmental sequence a child has either stopped maturation or has rested for a while. With blind children, experienced examiners can also develop a normal developmental sequence from which to work. Non-handicapped, intact blind children differ very little from an associative or cognitive language standpoint, for example, than a sighted group of sound children. The third purpose of assessment in this threefold structure is assessment as a way of helping a child to learn, thus viewing the evaluative procedure from a therapeutic and educational angle. From this viewpoint it is just as important to observe whether a child is able to learn a task as it is to find he couldn't do it to begin with and, after learning, if he can, one, recall the solution or adaptive behavior and, two, carry the concept over to a similar but altered situation, the latter piece of behavior being the one of highest order and the one most predictive of maturational level along any scale of developmental tasks for which one wishes to examine. This threefold purpose of initial and follow-up evaluative schedule must go further than traditional assessment techniques with blind children; heretofore---they have frankly, in my experience, been bogged down by an over-concern with merits and limitations of existing instruments, or even more to the point, the concern over the real lack of so-called standardized instruments. Rather, standardized procedures must be introduced, using tools, techniques and objects which reflect the developmental sequences I mentioned a few moments ago. What I really seem to be saying is that a multiple handicapped child constitutes a standardization group all unto himself, and thus needs a unique type of assessment which is based upon the standards of the normal sequence of maturation, but cannot be applied in an empirical way, only in a rational way. It is also likely that this child will need a series of assessments or an assessment schedule, if you will, most ideally in six-month intervals during the first 24 months, in order to attempt to plot the child's course through the developmental sequence and properly pinpoint "trouble stages" wherein special remediation from an expert may need to be introduced.

To conclude this short observation of mine, I should attend directly to the panel title, i.e., "Adapting Professional Knowledge and Skills to Service." Within this broad area of "Service" come one, the child, two, his parents or guardians, and three, the teacher or persons responsible for his formal development and education when out of his home. We have discussed the child himself up to this point. The "consultation team" and "assessment schedule" approaches must always include and use the parents or caring persons as an integral part of their work. There are many problems inherent in this simple, most obvious statement, not the least being the parent's availability, motivation and degree of effectiveness based upon emotional identification with the child. We cannot even begin to scratch the surface of this aspect of habilitation of the multiple injured child at this meeting. My personal feeling is that we owe it to the parents, no matter how resistent or difficult they happen to be, to reach out to them as much as we can, even to the point of providing baby sitters from agency funds in order to include one or both of them in the child's on-going assessment and program derived thereof. My last comments are directed toward the teacher, perhaps the most important person in the multiple disabled child's environment, at least from the standpoint of intervention and source of information. The teacher is most interested in knowing who is the child in psychological dimensions, thus teaching personnel are most likely early childhood development persons, and their backgrounds heretofore based primarily upon developmental data on the normal child. The teacher, when faced with a report from a psychologist (or other assessment person) on a particular handicapped child about whom she is most likely to be frustrated and perplexed, wants most to know how to translate the findings which tend to identify the psychological and medical characteristics of the child into meaningful educational and maturational goals, working around areas of sensory loss. The teacher asks for and needs help in deciding what goal she should set for an individual child. The assessment team must be willing and able to go beyond assessment and meet with teachers in order to help translate assessment conclusions and definitions into operational educational endeavors. She should be able to go to a consultant specialist and ask what is the best way of trying to get across a specific point to a child--in current educational jargon, what she wants to know is how to program the content of a curriculum for a particular multiple handicapped child. In the field of psychological assessment of the handicapped child, the results of examination are only valuable if they confirm or disconfirm how the teacher or remediator thinks about or deals with the child. All too often elaborate and expensive assessment procedures are carried out in the name of identifying the multiple injured child, but turns out to be irrelevant for the educating persons, including parents, teachers, and even the agency involved. Such old, seemingly irrelevant issues such as, are blind children autistic, is an example of this. Although interesting from an academic viewpoint, this does not really contribute to advising teachers how to cope with and devise remedial procedures and goals. In fact, teachers tend to become over-focussed on such concepts as autism, thus missing the important developmental issues. I strongly feel that the autistic-like characteristics in many of our blind infants and children are manifestations of anxiety based upon undifferentiated responsiveness to a sensory loss the child cannot comprehend. These motor responses become patterned and are discernible in the adolescent and adult blind population. Another result or observation which has become evident from our attempts to interpret meaningfully to parents and teachers is that our group of multiple handicapped infants and children can be very unpredictable in continuity of maturation. In other words, they grow, take a few steps backwards sometimes, and then several steps forwards, not staying in one stage or another as consistently as the normally sound child. The concept of "reaching a plateau" thus must also be discarded as non-useful---it tells a teacher or parent nothing and may serve to decrease their efforts with a child, waiting for the dormancy to disappear magically. There is not sufficient time to delve further into some of the interesting questions and findings we have given our attention to or the result of the ongoing team approach to assessment and very close observation on a longitudinal basis in interpreting results to teachers. These developmental questions are vastly more important and interesting than the traditional I.Q. scores associated with psychological assessment.

The Challenge of Educating the Preschool Blind Child with Multiple Handicaps

Mrs. Edith Patt, CSW, Supervisor, Children's Services
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Occasionally, I am fortunate enough to hear young people talking to each other and, sometimes, I listen. The other night I listened, casually at first, and then carefully, for I found myself thinking that they had much to say that might be important to us here today. The four young adults in the living room were discussing very seriously, despite the humor which was in evidence, the importance of "doing your own thing." At the same time they were concerned about the need for better communication and, although they didn't use the term, generation gap, I felt that was what they were talking about. It made me stop and think for at first it seemed that the two ideas were incompatible. But, after pondering it for a while, I began to realize that if the two concepts would go hand in hand, we would really have it made! They had given me my topic for today.

In dealing with the multi-handicapped child there are so many professionals involved in doing their own thing--doctors, nurses, therapists, teachers, social workers--and sometimes because of language stemming from a different discipline or sometimes because of a different approach to the same problem, there is a breakdown in communication which produces a professional gap which may not be helpful to the clients we are all serving.

We are here because we are interested in bringing together new ideas, approaches and experiences, so that the children with severe handicaps and their families who are also handicapped, can make maximum use of the professional help which is offered to them. I will address myself primarily to the role of the social worker as part of the team that is involved with the child, and I would like to elaborate on the role of the children's worker in a program serving the multi-handicapped child. It is easier, I believe, to see what a caseworker does when she is involved in giving concrete service such as financial assistance, placing a child in a foster home, or doing marital counseling. Because of our own experiences as pupils or patients, we all think we know what the functions of teachers and doctors are, but we have not all had the experience of being the client of a social agency. How does a social worker actually help? What are some of the tools she uses, how does "talk" become something constructive and not just conversation such as one might have with a neighbor or a friend? What does a social worker bring to the situation which makes hers a unique role, and how can her skills be used to enhance the "team approach" to the handicapped child?

We receive referrals from clinics, from schools, private physicians, and parents themselves, and it is not always clear why parents are coming to us or why they are being sent. But what is clear is that they are in need of some kind of help or service which is not being met elsewhere. A referral to an agency for the blind frequently goes something like this---the child has a diagnosis of blindness and another disabling condition; the child is not walking, talking or doing a number of things which his peers are doing--the family is at a loss as to how to train the child--they want to institutionalize him, or they don't--the mother is overprotective or appears uncooperative to suggestions made by the hospital or school. It can go on with all kinds of negative factors which seem to be inhibiting the child's development. The only obvious thing is that something is needed, and all we can say at this point is that we will take a look and see in what way we can help.

Our willingness to take a look can be the first step in reassurance both to the referrent and to the client for it carries with it the cumulative knowledge gained from previous experience with families of blind children with or without other complicating disorders. It carries with it a familiarity of community resources as well as an awareness of how people in trouble can be helped to use them. It does not always mean that we have the answers! But it does imply our readiness to help a family explore the avenues open to them and make a choice for themselves of what they would like to do about the possibilities which are available.

The first and most important step in working with the family is the formulation of what we call a "psychosocial diagnosis." This involves, firstly, taking an "educated look" and formulating some conclusions as to what the problems are and it leads to a plan of action or direction in which a treatment plan can be pointed. A psychosocial diagnosis is not a static evaluation or something which results only in the writing of a social summary to be sent to another agency. It is, rather, a dynamic approach to getting to know a family, how it functions, and the strengths and weaknesses therein. It is based on the establishment of a meaningful relationship between the social worker and the client. It is ongoing and changing, as the situation changes, and the stresses within the family are relieved or heightened because of both environmental and internal factors. The psychosocial diagnosis may show up a host of problems, both economic and social. Often there are other areas of instability which make the skilled social worker pause to examine them more closely and they do not always seem directly related to the initial problem of the handicapped child which precipitated the referral in the first place. It is this concern with the total family and their needs as individuals and as a group which enables the caseworker to view the child as a part of a larger picture. The child is never a client, patient or pupil alone, but part of a social group in which what happens to one person affects what happens to another.

There is nothing magical or mystical about the casework relationship, although it is a therapeutic one. It begins with meeting the client where he or she is. It begins with tuning in on what the client is asking for and how he sees his problem; and it implies an acceptance of him as an individual. Florence Hollis, in her book on Casework states, "By acceptance we mean the maintaining of an attitude of warm good will toward the client, whether or not his way of behaving is socially acceptable and whether or not it is to the worker's personal liking." [1] Because this relationship takes place in a neutral setting which is not

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[1] CASEWORK, A Psychosocial Therapy by Hollis, Florence - p 12
Random House, New York, 1964

involved in carrying out medical prescriptions or achieving academic goals, it can be used to compliment and support these other two services. Through the relationship between worker and client we can often see how the goals of education or medical treatment are not being reached by the client and the reasons for the client's inability to utilize that which is being offered to him and his child in the way of service.

Probably the most important aspect of this casework relationship is that the worker's role is non-authoritarian in nature. Because of early conditioning, all of us tend to view certain professionals--teachers, doctors, nurses, ministers and lawyers, as authority figures. With these people we have become accustomed to reacting in a specific way and we are not easily freed from childhood patterns of reaction. It is true, in beginning a relationship with a social worker there may be a carryover from the other behavioral patterns and a client may not grasp the difference at first. But, if the relationship is to have any real meaning and be helpful in effecting change, the social worker must help the client experience a new kind of freedom in expressing attitudes and feelings, even hostile ones, that cannot come out in school, hospital or clinic setting, for fear of service being denied.

An example may be seen when a mother is given a series of appointments at clinics for physical therapy, speech and hearing, pediatric followup, or any number of things. Or a mother doesn't seem to be cooperating with the school that is trying so hard to educate her child. It is frustrating, to say the least, to those professionals who are trying to help, to feel that they are doing everything possible and the family is apparently unwilling to do anything. Because of the specific focus of the facility in which a particular service is being offered, it may not be possible to see the total picture or what is standing in the way of fulfilling seemingly clearcut and simple procedures. It is here that the agency social worker can help not only to clarify what is operating in the situation, but can be useful in helping to effect change within the family situation which can enable them to take advantage of services offered. In the case of the client who does not know where or how to reach a service, the agency worker can be helpful in directing them toward obtaining it.

Sometimes when a referral to a social agency is made, it is expected that a total change will occur within the family. Suddenly the father will find a job, the family will move into more adequate housing, and social standards or behavioral patterns will meet those of middle-class morality which may be the goals set for the family by others. Although change can and does take place, it is most often not nearly so dramatic or immediate as many of us would like. Then the question is asked--how does talking about a problem actually do any good, and what is the social worker doing if she is not reorganizing the environment? The quality of talking is what makes change possible and it can best be described in the words of Charlotte Towle, "reflective discussion."[2] Reflective discussion helps to bring out greater awareness of feelings, attitudes and actions, which may be blocking either acceptance of the situation (in this case a handicapped child) or change towards more positive action. A caseworker is

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[2] "Principles of Intensive Psychotherapy," by Frieda Fromm-Reichmann, M.D. Preface is by Charlotte Towle; University Chicago Press, 1950

frequently asked for advice and sometimes offers it in the way of suggestions or outlining possible plans of action. But her greatest asset in helping a family is offering professional concern which the family can experience as non-judgmental and which carries with it a deep respect for their rights as individuals. It is an exploratory process in which client and social worker together seek the answeres to social and emotional problems which are confronting the family. It involves a two-fold approach and help can be given both directly and indirectly--to the client and to other team members working with the family. Communication in a free-flowing way should be kept open between client and social worker and other professionals. Because of her position in the middle, it is sometimes only the social worker who may be able to recognize that the longest way around may be the shortest route. Adding perspective to a picture which is sometimes incomplete or lacking in depth is the indirect service to the client that may enhance the variety of other services being offered to family and child directly.

In our work with families of multi-handicapped children, usually the mother is the key client. Although fathers are seen, it generally is the mother who is worked with closely and intensively. The relationship between the mother and worker may become, depending on her need, a deeply personal one in an attempt to help her function more adequately or more comfortably as the mother of a handicapped child. This involves seeing her needs as a woman, wife, mother, and member of a larger family and community, and determining how these needs are fulfilled or unmet by the environment. A woman who feels herself deprived and in need of mothering cannot function as a giving and accepting mother, able to withstand all the additional pressures which are put upon her by the burden of a handicapped child. The quality of mothering is important in the development of every child, but with the multi-handicapped it is even more crucial. The job is demanding and difficult and most people cannot do it alone. In the beginning parents are frequently so involved with medical problems that they are continuously busy with appointments and medical investigation. Their prime concerns are--will my child live, will my child be blind, deaf, orthopedically handicapped? When they finally know what the diagnosis and prognosis is, they are then faced with new concerns such as--will my child learn, will he be able to go to school, how will he learn to eat solids, how do I teach him to go to the bathroom? They are left with the total child who, hopefully, is to become a social human being. Often the family has suffered severe trauma because of their having the handicapped child to begin with and sometimes because of their earlier experiences in seeking help. Although it is the fault of no one in particular, endless clinic appointments, seeking appropriate facilities and waiting for answers, can be a harrowing experience.

Frequently it is at this point that the agency worker starts with the family. This is where her skill in making a psychosocial diagnosis comes into play. She becomes involved in getting to know the family and evaluating the quality and potential for mothering and working towards a plan which will not only serve the child best, but which will not be destructive to the rest of the family. Sometimes it is hard for those who are working directly with the child alone to know what the impact of this child has had on the rest of the family. For example, there are times when a plan to institutionalize a child may be made with the family, and yet it may appear to other professionals that the child might do better at home--or vice versa. No plan of any kind is ever an arbitrary one made by the social worker alone for the family. It is something which evolves out of the family's needs and their expressed desires regarding their own wellbeing. Because a child is never an isolated individual but part of a family group, plans must be made which, hopefully, will enable the whole family to live with some degree of comfort. A social study involves recognition of what the handicaps mean in this particular family, recognition of strengths and weaknesses and an ability to interpret the dynamics of the situation which seem to be impeding the progress that others may expect.

Handicaps mean different things to different families and cultural and ethnic factors are significant as well as individual personality structures. An upper middle-class educated family does not react the same way as an uneducated family on a low socio-economic level. A Puerto Rican family in the ghetto is different from a black family in a similar ghetto; an orthodox Jewish family reacts differently from a devout Catholic family; a woman with a strong husband reacts one way and an unwed mother another way. If the handicapped child is first-born, the problems are different from when it is a middle or last child. A father of a handicapped child reacts differently from a mother, and there are as many variations in reactions of fathers as there are among mothers. So many factors enter into a social worker's psychosocial diagnosis and all of these are elicited through verbal and non-verbal communication with the family during the building up of the casework relationship.

One of the things that makes social work different from the other professions is the awareness of timing as an internal factor. Educators talk about readiness in reading, pediatricians talk about readiness to walk, social workers talk about readiness in a more generalized way. It may be readiness to move, to change, or to begin to accept help, and a lot of work may have to be done with a family in exploring their feelings and attitudes before there is any readiness to move on behalf of their own child. It is this difference in the timetable of readiness which sometimes seems to cloud up the area of communication among the professionals involved in the team. A teacher may expect a child will fulfill certain academic requirements during a specified amount of time; a doctor may expect change with a prescribed series of visits or series of treatments. It can be very frustrating for those involved to see that despite all their efforts the results are falling short of the mark. By being aware of the internal timetables of parents as well as the timetables of other team members, the social worker can sometimes help to make the job of the others less trying or less difficult. By reducing anxiety levels which cause an already anxious parent or teacher to push too hard towards success in such things as toileting, self-feeding, dressing and walking, we can sometimes enhance the chances of success even though it may seem that it is taking too long. Sometimes a short cut turns out to be the long way around and a parent may need help in learning to wait, and waiting with someone is better than waiting alone.

I have dwelt here today primarily on the non-concrete areas of service and, possibly I should have dealt more with the concrete, but I feel those are the things that most of us can take for granted. I'm sure all of you here have asked a social agency for specific things for a client or child--low vision service and help with obtaining glasses, getting a talking book, referral to a clinic, or a host of other things. In some degree, service has usually been given but it is in the less concrete areas, it seems to me, that our role is not always clear. I hope that this presentation will in some way help to increase understanding and possibly open up questions about our individual disciplines and differences and how we can work more closely together to help our mutual clients.

From the Viewpoint of the Early Childhood Educator

Mrs. Berta Rafael, Consultant, Preschool Programs
United Cerebral Palsy Society of New York

Special education has reached a point of recognizing early education as a most important component of education for the handicapped. "Adapting Educational Knowledge and Skill to Service" must make use of the special skills and knowledge of the Early Childhood Educator. It is he or she who knows much about child development and who sees the early years not as a step toward kindergarten or grade school but as a period of special significance in itself. We believe, and there is data to support this belief, that learning potential decreases with increasing age. Therefore, if an impact is to be made on the developing organism we must reach children as young as possible. With non-handicapped children we take a global approach - a stimulating environment rich in sensory experiences with good dialogue and verbal interpretation from which young children will select and integrate as they grow. Out of these rich experiences the child derives an understanding of the ever larger world around him and means and methods to cope with his ever widening world. Out of these experiences also he learns to understand people around him and to interact with them. He is experiencing success, self-respect and respect from others.

Not so the handicapped child who has not yet experienced success, respect and self-respect on which to build the courage and motivation to face this so very complex world; nor has he experienced the usual positive interaction with the environment.

1. There is paucity of experience due to neurological and physical handicaps. He cannot absorb and integrate all available stimuli from the environment and this may lead to inadequate associational patterns.

2. It seems further that we here in New York City deal with lack of environmental stimulation for children from poverty areas and this is added to the disadvantages of the handicapped child. Furthermore, there may be language and color barriers.

3. Neurologically impaired children need to use new and unusual neurological pathways to learning - and we the educators become the guides to these pathways.

What kind of a person must the educator for these young impaired children be?

1) She must be skilled in task analysis.
2) She must know child development.
3) She must have experienced much success in her teaching career in order to tolerate the slow and often frustrating development of her charges.
4) She must be able to learn from trial and error.

5) She must be willing to ask for help and work closely with specialists from disciplines: medicine, psychology, speech, social work, etc.
6) She must be supportive of parents, incorporate their understandings and skills with their own child, learn from them and help them realize that her role is that of teacher, not just baby-sitter. This attitude is important in the eyes of the parents. They need to feel she is the central figure in the child's education and they must endeavor to send the child to school regularly (a special problem for many minority group families).
7) The teacher must be a person of courage who can cope with much hostility and many disappointments.
8) Here I want to stress once again that while the educator is an important influence, she must be aware of all other influences, such as the parental feelings, often mixtures of love, guilt, and rejection, and many other psychological phenomena which influence the child's daily life.

What kind of classroom or environment and what educational steps do we take?

1) I see the classroom as a place where I want a child to be happy - feel comfortable.
2) I see the classroom as a diagnostic teaching center, where every step has to be planned, evaluated for results and re-planned: guided by our knowledge of each child's abilities and disabilities.
3) It has to be a place where a child can experience success and become motivated to take increasingly more complex steps in learning. This will also help him grow in self-esteem.
4) It has to be a place where we provide stimuli for the available senses to compensate for losses. I see this take place in a circular mode.

Let me give an example of what I mean:

In order to help a visually handicapped child fully comprehend the "chaos" of a car, we have to help him learn from many different approaches. He has to learn that it is a means of transportation from one place to another, say home to school. He will feel the vibrations of the engines through his body and smell the gasoline. He may experience changes in air and temperature if his remaining senses are very acute. He must be made to feel the various parts (horn, wheels), inside and outside with names and functions simply explained. He can feel the heat of the engine. If his hearing is not seriously impaired he can hear the motor running. A model car may give him a total picture and eventually he will know a car.

is necessary to break tasks into small components so that success can be easily experienced. Each success has to be made clear to the child through our delight in his achievement. Gradually he will learn that he "can do" and know that he can fulfill our expectations of him. Here we are working with an advantage. Young children have a great desire to please those they like and on whom they depend. Our pleasure then becomes the child's reward and motivating force.

What kind of activities do we have to provide? All activities that will sharpen and refine all senses available to the child: touching, smelling, feeling, tasting, hearing. This can take place through carefully structured experiences like measuring, pouring, cooking, eating, planting, pushing, pulling, feeling. For instance, waterplay with large and small vessels can lead both to skills in manipulation and to conceptualizing of quantities. Feeling different materials from sandpaper to lace and velvet can lead to understanding of likeness and difference, to discrimination of various complexity and to generalizations. Using musical instruments can help auditory discrimination, lead to greater self-control through starting and stopping at signals, to following directions and many other pre-academic skills.

This can also take place through free exploration of environment, which must include the outdoors. Rolling in grass and touching plants will give a child a sense of the beauty of nature.

All this has to be constantly supported by naming and interpreting.

Hand in hand with the widening understanding of the environment, social interaction must take place and be developed.

We know that handicapped children have spent much of their lives in isolation due to their handicaps and the concomitant protection and overprotection afforded them. They often have spent much time in the comparative paucity of experience in the isolation of home or hospital. These factors may have led to behaviors difficult to tolerate in the group situation of a classroom. Behavior often has to be modified. Such behavior modification is closely related to the child's need for self-respect and rests on the encouragement and response received for desired behavior.

Self-help has to be developed and special methods and technological devices have to aid in this task. All this means constant evaluation and re-organization of curriculum. Questions that need asking include:

1) Was the goal set by the teachers reached?
2) What next goal is to be set?
3) If not reached, why not?
4) Was the goal too high or complex?
5) Was the method wrong?
6) Do sequences need changing? (Handicapped children may need different sequential steps from unimpaired ones.)

This is why it is necessary to have very small classes and a ratio of not more than a few (2 or 3) children for each adult.

What about the parents? In order to establish a close working relationship from the beginning, I recommend that teachers visit the home of each child before the child enters the classroom. This will establish the beginnings of mutual trust between parent and teacher. The parents will need to have this trust before they will feel at ease about separation from their child. The teacher will gain insight into the home environment and be able to guide and supplement with greater understanding. The child will know that the teacher has been accepted into the home and, therefore, may be a friend.

This initial visit will have to be followed by many communications, in whatever form, between home and teacher. It will also become the basis for the interdisciplinary approach so vital in our work. The parent will realize that social worker, therapists, psychologists and all others contributing to the child's growth and development, cooperate with the teacher in support of the child and his family.

I also recommend that parents or guardians visit the classroom periodically to see their child in the group and to observe methods and materials the teacher has found helpful.

I want to leave with some thoughts I struggle with daily:

1. While I realize that research is necessary and that funding has to be accountable and hard results must be available - do not let research become superimposed on your classroom!

2. During the early childhood years children are cute, lovable, easy to carry; physical tasks to be done for them are not much more unpleasant than for an unimpaired baby. But as the child grows older and help for him becomes more difficult to administer; people around the child develop less positive feelings toward him; he becomes, in plain words, more of a burden. It is therefore incumbent upon the educator and, all services related to the child's growth and development, to help him become willing and able to succeed in many self-help and learning tasks and it is equally important for the educator to do this in concert with the parents so that together all available forces within the child can be utilized for his maximum functioning.

3. We know there are in the development of children certain times of stress and the period we serve leads to just such a difficult time. It is necessary to provide additional help for the child and his family during such a time of stress. Let me tell you of one such incident particularly vivid in my memory --

> A totally sightless young boy had played with the neighborhood children in his backyard and on the sidewalk for several years. When he and his friends turned six, the friends began to move further away from their houses, learned to ride bicycles and were allowed to cross the street. My boy was deeply hurt and his school work suffered. Then came a day when he and his friends played together in the neighborhood and accidentally wandered on a freshly seeded lawn. When the irate owner of the lawn came out of his house, the children ran...... all but my blind boy. He did not know what was going on and

became the recipient of the neighbor's wrath. I arrived just in time to pick up the pieces....

In Summation:

We must, through carefully planned curriculum, through trial and error (because there is too much we do not yet know), through experience of success, through building a strong ego and through behavior modification, in harmony with all of those concerned with the child, help him to become someone who feels capable of doing some things for himself and who people like to be with, in spite of his handicapped condition.

Coordinating Services

Jerry Allford, C.S.W., Chief Psychiatric Social Worker
Psychiatric Clinic
The Jewish Guild for the Blind

We have heard something of the content of services from three professional areas: psychology, education and social work. The complexity of problems with which the visually handicapped child and his family need help often require not only these services but many others, including fields of medicine and community resources such as recreation, financial assistance, and homemaking service.

Experience in providing services when a complex of problems is involved has clearly demonstrated that when one aspect of a problem is pursued with no relationship to the total situation, the help is often ineffectual and indeed wasteful.[1] We cannot ignore the child's total environment if we are serious in our effort to help.

The visually handicapped child and his family are not unlike the multi-problem family much discussed in professional literature in the need for a variety of services from different professionals, frequently in different agencies. Too frequently the services provided by various professionals at the same time are reminiscent of the symphony orchestra at warm-up time. While strains of melody can be heard here and there, the total effect is discordant and unharmonious. As with an orchestra, each aspect of service to the handicapped child and his family must fit properly into an overall plan to be effective. While an orchestra is guided by music written by the composer and also a conductor, we must find our way case by case to achieve working harmony in services to people.

If we are to achieve harmony in provision of services, there must be mutual exchange of information among professionals involved, mutual understanding of roles, objectives, and mutual planning which allocates responsibility and determines priorities. This is the substance of coordinating services.

It is helpful to designate one person from the professionals involved as the principal coordinator in each case situation. This person could be the teacher, social worker, psychologist, or any other professional who can most effectively influence the various services to fit into the overall need of the child and his family.

The importance of involving the family in formulating plans is crucial. Too often we forget whose child this is. Too often professionals develop and pursue plans which they later learn the client and his family could not accept.

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[1] Interagency Communication by Elizabeth Rice - Social Casework, Vol. XL II #5 - May 1960, p 242.

> Betty W., a totally blind, mildly retarded young woman, had been referred to our agency for vocational services by the state rehabilitation counselor. The request was for mobility training so she could travel alone and then vocational training. Miss W. had received mobility instruction from another agency, but did not learn. Her father, who was quite vocal and demanding, complained the services given by the other agency were inferior. Referral material indicated Miss W. to be dependent and immature. After talking with the other agency about their experience in attempting to help Miss W. and her family, the social worker arranged a meeting with the state rehabilitation counselor, our psychiatrist, a representative of our vocational rehabilitation department, Miss W., and her parents. At this conference Miss W's views as well as her parents' views about needed services were elicited. Discussion and exploration with Miss W. and her parents revealed that Miss W's mother pushes her toward independence, her father encourages her to remain dependent, and that Miss W. herself is conflicted about dependency, and had not really wanted mobility instruction before, nor did she want it now. She had "gone through the motions" because it seemed expected of her. The need of the entire family for help in working through these problems was discussed, and it was left for the family to decide to which agency to go for help. The family decided to return to the agency which had previously worked with them.

Miss W. had had years of vocational, educational,psychiatric and social work services, much of which was wasted because they opposed the emotional needs of this neurotic family.

Communication among professionals and agencies giving service is crucial. A conference including all those giving services can be helpful in sharing ideas and information and planning for future services. Too often, however, we are deceived into thinking a conference has achieved coordination and mutual agreement when it has not. Face-saving, overconcern with others' feelings (or one's own feelings), hesitancy to express disagreement, rivalry, and other extraneous factors at times can obliterate consideration of client needs. Unless the participants can work freely, cooperatively, and harmoniously together, valuable ideas will be lost. When professionals can trust one another, exchange information, argue ideas, and make an effort to understand what each is trying to do and how, the atmosphere becomes conducive to testing out of different approaches, incorporation of new ideas, and comprehensive planning. Unless each person providing services takes responsibility for working cooperatively, however, effective coordination cannot be accomplished.

We should not have fixed notions about the composition of our team and the role of each member with a given client. For example, over the years, the social workers in our clinic have come and gone, while the school director has been with the agency over a long period of time and has known many of our adolescents since they were in our nursery school. It is not surprising that the parents of some of these youngsters bring to the school director problems and feelings which they do not take to the social worker.

Parents bring other ideas about the composition of the team:

> Jose B., a totally blind adolescent with a history of epilepsy, was in our school a number of years. According to our record, the family had never followed through with special medical examinations with our medical consultants and needed medical understanding was missing. The father explained to our social worker that his wife, who spoke little English, would be uncomfortable taking her son to visit doctors who spoke no Spanish, and she was reluctant to come to the mid-town area of the city. He could not take off work himself, but suggested his wife would be able to take Jose to their local clinic which the rest of the family attended for medical care. With his consent, the social worker contacted the clinic and learned the family was well known to the staff. The clinic, a demonstration project in a low income area, had a Spanish-speaking family health worker who had worked with the family. The clinic staff were interested in being helpful in any way possible and agreed to arrange the needed examinations. When the clinic worker learned there would be a long wait for an EEG, she called our worker, and together they arranged for the examination to be done by our consultant, but with the family health worker explaining the purpose of the examination to the family and accompanying the mother and Jose for the appointment.

A telling example of the lack of coordination as viewed by the client is seen in the following case illustration:

> Parents of a youngster referred to another agency described extensive history taking by the new agency. They had understood we shared information with the referral, and the father in particular resented giving the same information again and again over a period of years. Before the social worker could comment, the mother turned to the father to say, "This is the way social agencies work. You have to go along with it if you want to get service."

Many of our clients don't complain as did this father. They simply give up trying and are then labeled "unmotivated."

Unless we recognize the waste and confusion which results from uncoordinated services, unless we recognize the whole is made of many parts fitting into a meaningful pattern, we are giving less than those who need our help deserve. Ways of achieving coordination are many and can be found so long as those involved in giving service recognize the importance of working together to relate services to what families need and to what they can accept.

The following six presentations which constituted Session III of the program provided highlights from a variety of very special programs all of which have been devised to serve severely multi-handicapped children. In planning for this session it was decided that each of the teachers involved should take one area of educational interest and develop that area fully, but briefly. No one presentation is intended, therefore, to be descriptive of the total educational program available in the setting represented by the speaker.

Encountering the Environment

Mrs. Madeleine Appell, Educational Coordinator
Rubella Birth Defect Evaluation Project
New York University-Bellevue Hospital

I would like to tell you a little bit about our program at Bellevue Hospital. The educational program has two components. The first consists of two sets of children grouped on the basis of developmental compatibility who are seen twice a week in the morning. The second component consists of children unsuitable or incompatible to the group structure who are seen for individual therapy in the afternoon. Because we have no transportation, the mothers in the group program must bring their children to the hospital. They are required to remain and work in the schoolroom as "teacher-aides." Most of the children in the group program are functioning on a very low developmental level, no higher than 12 months. Motor performance is their most advanced area. Of the eight children in the group, two walk independently, one is independent in feeding, the remainder are totally dependent in all areas.

I would like to tell you about our sensitivity training program which is kind of a little Encounter Group for the children. Our consultant is William Schutz. We want the children to experience the "joy" of encountering their environment. Kidding aside, this is primarily a sensory stimulation program with emphasis placed on motoric exploration of the environment with the major means of gathering perceptual information being tactile and kinesthetic feedback. Sensory input through these particular channels forms the basis for a part of the program we call "media experiences." As all the children, at this point in time, were functioning on a primitive level, we tried to gather together materials that would be appealing, compelling, and, most important, would provide the tactile and kinesthetic feedback that we were looking for. For instance, we have made collages using ten different kinds of foodstuffs: corn, lentils, cereals and macaroni of varying sizes, shapes and textures. This is particularly important because the mothers now realize that most of our "educational" materials are familiar products purchased from the local supermarkets--that these very same products are to be found in their own kitchen cabinets. What we have tried to do is show our mothers that providing a stimulating environment for their children does not require "professional" knowledge, "skill," or a great deal of money. How did we do this? We began with chocolate pudding. We discovered that if we cut down on the amount of milk used, chocolate pudding is fantastic for finger-painting. We also use vanilla and butterscotch puddings, "Cool Whip," and "Whip and Chill" for variety. Although chocolate pudding incorporates all those ingredients requisite for a multi-sensory experience, our children did not voluntarily interact with this medium. Therefore, we actively encourage interaction by manipulating their hands and by passively bringing their pudding-smeared fingers to their mouths. This is possible because we always maintain a one-to-one adult-child relationship. We have purposely chosen materials that are edible as we wish to encourage oral exploration. In addition to puddings, we have used bananas and oranges to provide further opportunities for multi-sensory exploration and stimulation.

I would now like to move on to discuss with you what we call our "feely" walls, so called because these foodstuff collages were designed to be mounted on the schoolroom walls. We had the children finger paint on flat sheets of corrugated paper with wheat paste which, of course, is edible. The children then were given cereals to drop onto the pasted surface. Upon contact, the cereal stuck to their pasty hands. At this point, some of the children, to our great joy, began picking it off with their free hand; but others just sat there, hands and arms great masses of wheat paste and cereal, totally unrelated. Though a good sensory experience, these wells have not been too successful. We found that the paste did not adhere well and, as a result, the walls fell apart. . .Oh well, "feely" floors. Nevertheless, we do intend to repeat this project -- with a stronger, but still edible, adhesive.

We move now from walls to mobiles, or "feely" balls. Each child covered a balloon surface with multi-layers of papier mache. This was a very exciting experience for us because for the first time one of the children actually interacted with the material and independely covered a balloon with strips of papier mache. When the balloons dried, we painted and shellacked them. We then took everything we could find - feathers, shiny paper, ribbons, pieces of material, and had the children paste these onto the balloons. The balloons were then strategically hung about the room at a low level. After about three weeks, one of the children actually became cognizant of the object he had been continuously colliding with. That particular ball then became his favorite toy. Upon entering the room he would immediately rush over to it to begin pushing and catching it as it swung back and forth. He would be laughing and giggling the whole while. At this point, I think all of the children are now aware of the mobiles. We made another series of "feely" balls on which we pasted beans and corn. This is all part of a sensory assault to force the children to bump, feel, taste, see, and eventually acknowledge and hopefully interact with their environment. We carry this same aggressive philosophy into our motor training program which is under the direction of our occupational therapist, Judy Abe. In this program the children are stripped down to their diapers and are rolled about, first on top of a small beach ball and later on a very much larger one. These children have no sense of self, no body image and, therefore, no sense of gravity. If they fall, they have no feeling of being off-balance and exhibit no righting reactions or protective responses such as putting out their hands to break the fall. In fact, the only response they exhibit is a startle or a cry at the displeasure of suddenly hitting the floor or mat with a jolt. The therapist is trying to give them some body awareness and sense of balance by rolling them on the ball. She wants the children to begin to clutch the ball, hold on, or reach out in response to being purposely put off-balance. The therapist also takes macaroni, slips it onto the child's toes or fingers, and encourages him to pick it off. By doing so, she is enhancing the child's awareness of his body parts and helping him to make some meaningful contact with them.

The children in our school program hold exclusive membership to the Bellevue Beach Club. The Club is located on the seventh floor of Bellevue Hospital adjacent to the schoolroom and the children's orthopedic ward. It is actually the tubroom used by the in-patients on this ward. After we complete the many dirty activities of the day, we take the children to the tubroom for "swimming." The bathtub has turned out to be a real boon - it is so small that when we put four or five children into it at one time they have to make actual physical contact with each other to move. We dress the children in bathing suits, splash them and blow bubbles on their bodies. They must touch their bodies to break the bubbles; they must touch each other to get out of the way of the splashing. This activity serves two purposes: 1) to help the children develop a sense of body image. 2) to clean them up after the day's activities.

To sum up, most of the materials we use are purchased at the local supermarket - they are inexpensive, they are pragmatic. The parents remain and participate in the educational program so they can see what we do and the materials we use. We try to demonstrate to them how to accomplish the same results at home. It's a mess, but it works.

Some Practical Approaches To Activities of Daily Living

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The other day a group of visitors came to our school. One visiting young lady commented, "But we are working with severely handicapped children. They are nothing like yours. Ours cannot do anything for themselves. They don't eat alone. They don't sit on the potty. Some don't even walk. Why, your children are nothing like ours." I smiled to myself when I thought back to only one year ago when I felt as she did. The severely handicapped four and four and one-half year old Rubella children did none of these things.

Today I am going to discuss some aspects of self-care skills of daily living. The basis of my discussion will deal with the practical aspects of these areas and, although 100% success has not been achieved - far from it, in fact - with the children we are seeing, enough progress has been noticed which encourages us to continue along the lines that we are presently employing.

The theory behind teaching the developmental order of feeding and toilet training is that every stage that the normal child passes through must also be reached by the handicapped child. The time of arrival of each stage is markedly delayed. The multi-handicapped child will, hopefully, follow the same maturational landmarks as the normal child. He will arrive at each step in development at a much later period than in the normal time pattern and the skills must be taught. Our aims are the ultimate goals of self-feeding and toilet training.

Multi-handicpped children have all the ordinary needs that all children have. However, they do need extra attention because of their specific handicaps. Often a parent is so overwhelmed by each handicap that she cannot see the total child.

Food does much more than feed the child. It helps the child learn how to use various parts of his body. In eating, the child uses his mouth, hands, muscles of his throat - and some of our children use their eyes. Feeding is one of the first ways that little children get to know their parents. One often thinks of teaching as a rather formal approach. However, in teaching a multi-handicapped child to eat there are no set patterns, but there is an extension of mothering. Either hold the child on your lap or make sure he is secure and comfortable in his seat. Try to keep him in a sitting position. Encourage the child to taste even if it takes a little forcing in the beginning. Many of these children do not know that food can be enjoyable.

With children who had trouble swallowing, we have been successful in offering them cream cheese or peanut butter. They have to experience with moving their tongues. Sometimes you can help by placing food in the back of a child's tongue and gently stroke his throat downward. You can also place the food on the back teeth where it has to be chewed off. Very slightly, dilute the strained baby food with either milk or juice and then gradually work it up to a consistency where you crumble graham crackers into the food to thicken it. Then you can work up to additional solid foods such as bananas, canned peaches or pears, because they are smooth enough and can be swallowed in small amounts. In helping the multi-handicapped child to learn to chew, it may be helpful if you put his hand on your jaw and show him how to make the up and down movements. It is a good idea to put some food in your mouth to show him how it's done.

Remember, not all children are alike and what you may do with one child you may not necessarily do with another. You may have to try various ways until you find out the best method that suits each particular child.

Try to encourage the child to feed himself no matter how messy he may get. Some children begin feeding themselves with the tools with which they were born - their fingers. However, the blind child may need encouragement to put his hands in the food. This does not always come naturally. Many multi-handicapped children do not do this on their own, but need encouragement to use their hands. Table manners will come later. When he is learning to eat, it is a good idea to serve him by himself. Then later on when he is able to sit at the table with older members, he may learn by imitation. However, this is not true for the blind or very retarded child. The companionship and cheerful atmosphere are good for him.

A child should be able to swallow liquids and then solids before he is allowed to feed himself. The shape and size of the spoon and sometimes the length of the handle may often play a big part in the success of eating. Place a foam hair curler on the handle end of a spoon. This usually helps the child get a good grip on the spoon.

Our staff has found some of the following suggestions helpful:

1. Give small amounts of food.
2. Never make a fuss if the child refuses, offer him some again soon.
3. If he should refuse to eat, do not allow yourself to become upset. He will survive.
4. Do not allow snacks between meals. A cup of fruit juice or crackers in the mid-morning or afternoon should not spoil his appetite.
5. When he can handle a spoon well, teach him to use a fork.
6. Make mealtime a calm and pleasant occasion.

Many children came into our Rubella program still using a bottle - but parent counseling has been helpful in guiding the parents to accept the transitions to baby, to junior, and to solid foods.

Toilet Training

We provide many opportunities during the day for the children to use the bathroom facilities. As soon as the children come in, whether they are dry or wet, they are put on the potty for no more than five minutes. In our setup, we use individual training chairs because we only have access to one adult-size toilet. As they progress in toilet training, we gradually introduce the use of the regular toilet.

Each adult is made personally responsible for the toilet training of two children. They keep a record of the hours at which he is wet or had a bowel movement. Each child is placed on the potty at regular intervals - some before lunch - after lunch - before or after their nap - before they go home. In this way we try to anticipate each child's needs. It is also a good idea to take the child there even when he or she had just wet or soiled his diaper or panties. This will help to strengthen the association in his mind. We make sure to replace the wet diaper or panties in the bathroom.

When the child seems to understand the purpose of the toilet facilities, make sure he has easily removable clothing. We have found it advisable to introduce training pants at this point. You will then watch for signs that he wants to go to the bathroom - such as squirming, holding himself, moving up and down, or whimpering. As soon as this happens, take him to the bathroom and try to show him some form of approval for his gesturally expressed needs. Everytime the child is successful, he should be given a great deal of praise and approval. He should be praised with a hug, a word of approval, clapping both hands together, etc. Make sure you wash his hands each time he uses the chair or soils his pants. This can serve as a reward if he enjoys putting his hands in water. (You may wish to establish a sign or gesture indicating that need or procedure of going to the bathroom.) If so, use it consistently. Try to be consistent.

Our staff has found some of the following suggestions helpful:

1. A low stool in the bathroom will help him reach an adult-sized toilet or washbowl and make self-help much easier for him.
2. A small size seat attached to the regular toilet seat will make the child feel more safe and comfortable.

Some of the ways we try to stimulate urination are:

1. Flushing the toilet bowl.
2. Letting the water run.
3. Letting the child keep his hand in water.
4. Giving him a drink of water.

One little girl comes in dry every day and goes home dry. This does not necessarily mean that the child is toilet trained because she does not indicate when she has to go. After putting her on the toilet at regular intervals, she finally performed, but with an over-abundance of urine. Since this exceedingly large amount seemed suspicious, I asked the mother to save a morning specimen and we would send it out to be analyzed. At the present time the child is in Bellevue Hospital being treated for a kidney infection. This is just an example of how a medical problem was noticed through our toilet training program.

One youngster does not wet his pants, but he likes to urinate on occasions at doors, walls and in front of the mirror. One attempt at discouraging this atypical behavior will be to bring the mirror in front of the toilet. The importance of carry-over at home is emphasized to the parent and coordinated with the social worker attached to the program.

It sometimes takes a very long time before a child indicates through gestures his need to use toilet facilities. One day a child who had never been able to demonstrate his needs suddenly, in the midst of an activity, started to cry. Because the crying came near the usual toilet training hour, we took him to the bathroom and he performed. We felt this was the beginning of awareness. This was later corroborated by his mother. We feel that we are on the road to successful toilet training.

It is impossible to predict how far these Rubella children will progress - but their progress is no longer an impossibility. The children in our unit have progressed steadily and developmentally since the first days of our training program. We do not know if they will ever reach the individual goals set up for them, but we do know that they are now functioning on a much higher level than had ever been predicted for many of them.

Early training and guidance have been the crucial factors in this development. We try to be realistic. We are aware of our children's limits. But we will continue to strive toward the attainment of goals which are goals for all children.

We will continue to develop and strengthen their independence in self-help skill areas. We will continue to train these children into socially accepted behavior. We do not know how far they are capable of going - but we will continue to help them along the way.

The Willowbrook Program

Mrs. Dolores Mason, Educational Supervisor
Willowbrook State School

We at Willowbrook have for many, many years been concerned with the problems that have just been cited. For many years there has been nothing in the way of programs for very young multi-handicapped children and, therefore, Willowbrook has been confronted with the problem of having very severely handicapped and profound mentally retarded patients. We have had head-bangers, the destructiveness, irritability--the whole gamut of problems that result when there is no attempt at stimulation and no program for the retarded handicapped child at a very early age.

Within the last seven to eight years we have decided to try to undo all of this. Our plan has been to start with the very young children admitted. We must face the fact that Willowbrook has, since its inception, been the last resort for the children who are placed there. We started with the youngest children in the hospital with the thought that we could prevent their sitting, rocking, oblivious to their surroundings, requiring tremendous amounts of personal attention and care from both the professional and the para-professional staff, and requiring periods of restraint as well.

Our first emphasis has been on the wards working with the ward attendants who are responsible for the children for the greater part of every day and on a shift basis and who spend most of their time with the children and know them better than any other personnel in the hospital. We build upon the apparent innate ability and care for children that is shown by the ward attendant by training her our motivation program. We take her out of the ward situation so that she is not concerned with cleanliness, with making beds, with sweeping floors, with physical care of children, and we give her a fifty-hour training course in how to work with small groups of children who, incidentally, are not included in any other program. We teach the attendant how to get these children to interrelate with one another, to develop a concept of self, to develop an awareness of their surroundings, and how to use the various sensory modalities. We find that this program is working and that the motivators are able to get these children ready for other programs. By the time an infant has been admitted and by the time he has completed his evaluation and been fully worked up, the child has some awareness of what it is like to be in a group. The whole program revolves around motivation for learning and personality development because these children must be given the essential concept of self, the dignity of the human being, the feeling that they are people. Without this we can do nothing.

First we depend on the motivators to establish this concept with the very young children. Then the children start coming into the infant therapy unit where they are then evaluated by a physiatrist who will place them either in physical therapy or occupational therapy. Physical therapy is primarily concerned with getting these children on their feet and off their back, from the prone position which is seen when they are left lying on the wards. Incidentally, this situation of children lying on their back or prone in a crib actually multiplies the child's handicaps, especially in an institution where a child does not have the advantage of having parents who can bring stimulation to him. We cannot expect the nurturing, the emotional bond that exists in the home with young children in the children who are patients at Willowbrook. This is especially true of infants and children admitted at a very tender age who have missed out on the emotional bridge on which all other learning is based. In occupational therapy we have the whole gamut of feeding, training, of sensory development. In addition, if these children have a hearing loss they are at this point working up and, if possible, fitted with a hearing aid so they can benefit from other forms of stimulation. These children are also admitted to recreation where we have them rolling on mats, some of them standing up in standing boxes necessary to keep their back straight. We must remember that in dealing with these severely and profoundly retarded children we find a high degree of other anomalies as well--they are not merely Rubella children, they are truly multi-handicapped and, in addition, have the emotional deprivation of institutional placement. Everything that can be expected at the bottom of the ladder is found in our patients.

By the time the child has moved well in the skills of daily living program, he is considered ready for the school program and is transferred to a learning situation where we start all over again basing our teaching on self-identification, relationship between student and teacher, and we start moving into the area of inter-personal relationships. We place great emphasis on language development. We know that when a child can't move and is not aware of his body, he doesn't readily talk. When these children reach the age of six or seven, even though their mental age is much lower, if there is no language then they must actually be assaulted with a barrage of language development, material of almost every possible kind. They start at the babbling stage and it takes a great deal of effort and a great deal of structure to bring this to a more meaningful kind of language experience. In addition, we try to broaden the experiential background of the children. As soon as they have developed some minimal self-help skills and they are beginning to show some sign of language development, we get them out of the institution on field trips. We want them to interact with people in the community. For instance, we are becoming more readily accepted by public schools in the area who send their children in to Willowbrook to give parties for the children who are patients. Some of the better children are actually able to differentiate these experiences and talk of when they were outside and some of the things they did outside and "when they are going home" or "when they were home," and these are the proof of the value of the program.

Music, Movement, and Mobility

Three Aspects of a Pre-School Curriculum for Multi-Impaired, Primarily Blind Children

Mrs. Louise G. Hodell, Educational Director
Child Development Center for Visually Impaired Children
New York Association for the Blind

One of the more distressing realizations that intrude constantly into the consciousness of all those who try to help multi-impaired infants and preschool children is that even children of one, two or three years of age have so much to learn and seemingly little capacity for voluntary or natural learning through exposure to the usual experiences of family life and nursery school. Unlike their intact peers, impaired children frequently do not seem to absorb knowledge about the world around them easily nor do they learn social behavior and speech through imitation and emulation easily. They often seem walled-off from the busy activities of family, siblings, and every day life. They can seem unable to learn the multitude of basic concepts that enable better endowed children to grow, to initiate activity, to copy, and to reach out into the environment for pleasure and the satisfaction of curiosity. Often, the impaired child appears all too happy to be left alone, shut up in his own little restricted cocoon, passing his hours in self-stimulating activities that are not productive of further learning.

Professionals charged with the responsibility of doing something about the retarded skill development that results from cognitive and sensory deprivation, fall back on the term "intervention" to describe their educational efforts and programs. Not only is it necessary to "intervene" in a growth process that is going wrong. It is necessary to "intervene" in a process that has encapsulated the child's mind to such a degree that it becomes, literally, quite necessary to break through the wall. The concept then of intervention is most appropriate, but the problem of how to effect necessary and corrective educational intervention for very young children remains frustrating and challenging for all who attempt to do it.

The philosophy and working hypotheses of the staff of the Child Development Center for Visually Impaired Children of the New York Association for the Blind accepts the responsibility for experimenting with and pioneering new methods of intervention for the multi-impaired clients and their parents. It accepts and assumes that a child's total development can be restricted and adversely affected by the loss of one faculty. Furthermore, it has been observed through the rather comprehensive diagnostic evaluation program of the Center, that the child with only visual impairment, or auditory impairment, or any other single impairment, is rare indeed. Whatever may have caused the most outstanding deficit, probably affected other parts of the child's physiology, sometimes in forms difficult to observe and diagnose, but forms which nevertheless increasingly incapacitate the child's ability to learn as he gets chronologically older.

While my assignment in today's discussion has been to describe the Center's program for teaching Music, Movement, and Mobility to multi-impaired, primarily blind preschool clients, I would like to digress for a moment from a description of those aspects of the Center's curriculum to mention what the staff consider to be the most important area for educational concern, the area of language development.

The search for methods to develop language in children who are also slow in this basic skill receives top priority in our work for many logical reasons. The most obvious reason comes from the recognition that development of language literally explodes during the preschool years and slows down thereafter, with the frequent result that measures of intervention in language education are much less productive after the preschool period has been passed. It follows that if absent or inadequate language development in a young child is to be remediated, intervention must be started early and follow through consistently in a preschool curriculum.

A second reason for an emphasis on language training in a preschool curriculum for multi-impaired blind children is the fact that learning in all other curricular areas is transmitted primarily through language. The three areas assigned for my discussion today, Music, Movement and Mobility, are heavily affected by a blind child's ability to understand what is given to him verbally. Since blind and visually impaired children cannot, or are restricted in, their ability to imitate what they see others do, learning to understand spoken language rather than visually motivated imitation is most important to them. They also need to be able to cope with language just to begin to understand the barest physical facts about any environment they may find themselves in, such as where the door is, who has entered or left the room, in which direction they can walk without bumping into furniture, etc. The interrelatedness of a blind child's ability to learn through language and his ability to understand how, when, and where to move his body, and his sense of orientation and comfort in any environment is therefore obvious and does not require elaboration here. In a similar vein, his concepts of space, distance, height, weight, temperature, sequence, causality and time (to mention only a few), are intimately interconnected with his ability to develop language. Concept and cognitive development will remain deficient if language, in the broad sense of understanding symbols, does not occur. Therefore, language development receives priority emphasis in all educational service offered at the Center.

MUSIC AND MOVEMENT: A Revised Curriculum for Multi-Impaired Children

In the Fall of 1968, the staff of the Center in cooperation with a music therapist from the Lighthouse Music School, began to plan a whole new approach to the challenge of teaching music to multi-impaired blind children or preschool age. Recognizing that the children needed extra help in understanding the world around them, the professional staff tried to pull together all knowledge and insight about how very young children learn, to fashion an ongoing music training program that would stimulate the acquisition of skill in many areas but especially in speech development and the ability to verbalize, mobility and awareness of the physical environment, and auditory sensitivity, in addition to learning to enjoy music. All of the songs, games, and musical experiences of the children were re-examined to determine their appropriateness for teaching very young multi-impaired blind children.

Lyrics of familiar nursery songs were re-written and simplified so that children with language impairment could understand them. Use of recorded music was restricted and finally ruled out almost completely because the music and language of children's records was found to be too complicated. Teachers and other staff members were taught how to use their own voices and/or simple instruments such as the auto-harp, so that the children could learn through live music and direct personal contact with the teacher. Musical activities that required body movement were given priority emphasis because blind children need to have many opportunities and much encouragement to use their large muscles in skipping, hopping, running, jumping and dancing. Learning how to move one's body through space also has crucial implications for the development of independent mobility, for a sense of orientation in rooms or on the street, and for sensitizing auditory acuity for later formal mobility training. In the same manner, songs, playing simple instruments, and simple rhythmic exercises such as clapping, all receive emphasis because of their important implication for reading and math readiness and the development of verbal communication.

The ratio of staff to children during music lessons had to be changed, so that the child who wanted to participate could be helped to join the musical activities through the personal and individual help of a concerned adult right beside him.

The children's positive response to the revised music curriculum has been evaluated through the children's demonstrated mastery of many simple skills. Their ability to attend and answer when called on, their ability to use simple musical instruments on cue and in the manner instructed, their ability to associate experiences of every day life to the lyrics of songs, has been increased. The most obvious indication of the success of this program has been the very evident pleasure with which they participate and their eager anticipation of the music lesson and the music therapist's visit. Their struggle to cooperate in all the music and movement tasks asked of them during music lessons is impressive.

The program is now in the process of being repeated, refined and extended so that, hopefully, the children's learning will be consolidated.

MOBILITY AND ORIENTATION TRAINING

Just as the curriculum for music and movement had to be examined and revised, the procedures for mobility training also had to be re-considered. Professional literature on the education of the blind was researched in an attempt to find recommendations of other educators who have trained young blind children in orientation and mobility. Almost no studies of comparative training procedures and few description of thought-out, structured programs for the preschool child were found in that body of literature. Why this paucity of information? Is it that mobility and orientation skills a_e thought to be unnecessary for young blind children?

More likely, the need for training in these skills has been recognized but programs have not yet been created to meet that need.

The persistence of questions about a recommended age for the beginning of mobility training and the documented evidence that blind and visually impaired adolescents show marked differences in ability to cope with mobility and orientation tasks, tends to indicate that greater and lesser degrees of learning in those areas take place in the early childhood years. Apparently, such skills are being absorbed prior to adolescence.

Basing their thinking in some general principals of early childhood education, the Center's staff began to formulate a theory and philosophy of mobility training and orientation to the environment for young visually impaired children. Essentially, the theory recognized that such skills are being learned in early childhood and even in earliest infancy, that achievement in these skills areas can be and should be reassessed constantly to determine if the infant is developing adequately and, when deficiencies in these skills become evident, measures of educational intervention should be applied as soon as possible.

The theory takes into account the fact that sighted, unimpaired children master most of their mobility and orientation skills before four years of age. Indeed, the classic "toddler" can be described as wound up like a mechanical toy, driven to cruising around his environment, crawling, climbing, running, and fitting his body into impossible spaces between furniture.

If skills of movement and an understanding of how to move in his immediate environment are mastered so early and helped by such a strong drive, then it seems logical to apply efforts to aid the impaired child in these areas of development at the chronological age when he, himself, is most motivated to acquire that kind of knowledge and skill, not later. It may even be that skills taught long after the natural and optimum period for their acquisition, can only be inadequately learned and only through much more exhaustive effort on the part of both the child and the adults who attempt to teach him. This theory places tremendous responsibility on the adults charged with training young impaired children in any area of development, but especially those attempting to train movement and awareness of the environment.

The Center's theory further recognizes that many kinds of simple, yet interrelated experiences are necessary to build a foundation for later formal training in the techniques for independent travel. It requires no specific tools or paraphenalia. The introduction of the cane, optical, and other aids is still delayed until the child is older.

The training consists of helping a child to become more aware of his environment through more accurate and skilled use of all of his remaining sensory channels. Auditory, tactile and kinesthetic channels must be sensitized so that the child can make maximum use of the information about his environment afforded through them, damaged though they may be. Even children who are severely visually impaired can be trained to make maximum use of whatever vision remains, but they will need help in organizing and understanding the limited information available through the impaired visual channel.

Adults (parents and teachers) are most important to this process of helping children become more aware of the information available through remaining sensory channels. They explain to a child what he is touching, feeling, seeing, hearing, smelling. Without such help the child can suffer unnecessary and often incapacitating confusion.

For the child who is also more or less language impaired, adults can simplify or tailor the language used so that the information "gets through" to the child in a form comprehensible to him. This is where the Center's emphasis on language training can be seen to interrelate with its emphasis on acquiring mobility and orientation skills. Even retarded and/or language impaired children can have their environment and experiences explained to them and made comprehensible if the adults understand the language difficulty and tailor their speech accordingly. Ultra-simple subject or subject-verb sentences can carry the message of what a child is touching, hearing, feeling, experiencing, and thus convey information that might not otherwise be available to the child. Long phrases and whole sentences often miss their mark and only serve to confuse young impaired children, so that sensitivity on the part of the adult in how to communicate with the children during mobility lessons is important also.

Just as at home, mobility and orientation training at the Center must take place throughout the child's day and must be integrated with many other kinds of lessons. At the Center it has been integrated and promoted during music lessons, quite consciously. The children are taught songs requiring specific body movements (clapping, jumping, shaking, etc.). They are taught to identify specific parts of their bodies and asked to demonstrate and describe movements that feet, arms, head, etc., can make. Through music they are taught such basic mobility concepts as stop/go, up/down, walk straight ahead, turn around, on the other side of you, etc.

In addition to an all-day-long mobility emphasis at the Center, children are offered specific and individual mobility training sessions. These usually consist of trips around the Center's building, trips to nearby stores, and parks. Often children will go out alone with an instructor, but when groups of children make a trip together, a ratio of one adult to each child is provided to individualize the mobility experience for each child. The Center's staff has grown to feel that only through such personalized efforts do the children benefit appropriately. Their extreme youth and somewhat confused idea of their environment, and their highly unique learning styles, render such a high ratio of staff to pupil advisable, if the children are to gain the maximum amount of knowledge from a mobility experience.

There are many other times during the child's school day when mobility and language training are integrated with routine school procedures. Gym periods and the opportunity they afford for practice and experimentation in motor coordination tasks, swimming lessons, periods for practice in self-care (dressing to go out to play and setting the table for lunch), arrival and dismissal in the school car, are all utilized to the maximum.

It is not possible within the scope of this discussion to go into the speculation of how the integration takes place, recommended speech patterns of adults, some of our observations about the hierarchical levels of achievement that the children seem to go through, and other pertinent professional concerns. More of the technical aspects of these processes are now being developed at the Center and eventually will be described for dissemination to the field.

The dearth of knowledge about remediation of the inadequate growth and learning processes characteristic of multi-impaired children is still overwhelming. We can only hope that our exploratory daily efforts will eventually lead to creation of more sophisticated methods of intervention that, in turn, will make it possible for less well endowed infants to bridge the gap between their achievement and that of the relatively unimpaired.

Aspects in a Multi-Developmental Program for Multi-Handicapped Infants

Miss Barbara Cashier, Infant Program Coordinator
St. Joseph's School for the Deaf

Visual Stimulation

One of the first steps necessary in our working with very young Rubella children who also have a visual handicap is to try to get a very complete picture of the eye condition and find out which cataract, if they are bilateral, is the more dense and which one may permit the greater use of light. We then zero in on that eye with as much visual learning as possible. We use light a great deal, but not light for light's sake. We're pretty sure that the majority of these multiple handicapped infants are going to have some language impairment and those of you who have worked with these children know the problems of perseveration. Light, therefore, was used as a means, not an end. We advised that a small light be kept on in a dark room all the time so that the baby be constantly stimulated visually while he is awake. It is positioned so that he is not staring at a light bulb. A small light on a brightly colored toy or object or whatever it may be is attached to the crib on a mobile.

Now many of these parents are very poor and it is necessary to help them make homemade toys. For example, soda cans and the like containing various noisy materials, were covered with brightly colored wrapping paper and hung over the crib so that the child would have them to look at and, hopefully, be attracted to handle them. When we have the infants at the school we use a light on all of the objects from his bottle to his shoes, on all of the toys and, most essential, on the face of the parents and the face of the teacher. This is the basic thing - human contact - the social importance of the human contact with the parents and teacher.

We found that these babies, most of whom were under a year of age and had not yet had the cataract operation, learned to focus. They demonstrated this, for instance, by our presenting a colored object such as the bright ball in front of them and their reaching for it. This is not just vision alone, this is reaching out - it is encountering and, of course, the greatest delight was when they would reach out to the face of their mother, which was what many of them did. The other thing that some of these children were able to do before the cataract operation was to track. For instance, one baby was able to track the light of a flashlight on the colored keys of a xylophone. Another valuable aid was a blownup plastic totum pole of red, yellow and blue. We found that the babies liked the red and yellow just about equally, but didn't go for the blue. When the blue was illuminated, their eyes dropped.

Another very essential thing for stimulation of vision was the use of contrast. This can be either light on dark or dark on light in order to emphasize the object you want to bring to the attention of the infant. In total, we simply seek to train the babies' residual sight as soon as possible. I cannot help but remark here that having heard the previous speakers talk about the older damaged children they teach, that I hope what we are doing now will be a preventive program so that even if these children need to be institutionalized later on, they will be able to function on higher levels. We feel that by teaching these children at this very early age to focus and track, their visual adjustment after cataract surgery will be better than if they had been without visual stimulation until the time of the cataract surgery. We have to recognize, too, the extreme difficulty under which our families operate in providing this visual stimulation, especially in the very badly illuminated flats in which most of them live.

The question has been asked about how we manage lighting. We have used low-intensity lighting on an object. At first we even blackened the room because fluorescent lighting was entirely too much and prevented these children from focusing. We also were very careful to find the kind of lamp that does not generate a great deal of heat since we wanted the children to reach out and we did not want them to be frightened by the experience of being burned should they accidently touch it.

Auditory Stimulation

In the area of auditory stimulation, most of you are familiar with very essential basic things used -- the mother, the baby, the holding, talking, singing, babbling to the infant. For many of the infants that we have served, we had no knowledge of what they truly were hearing. They were followed very carefully by Mrs. Rabinowitz at New York University Clinic and she had some indications, but for many of the infants, we just couldn't be sure especially where there was such multiplicity of handicaps. We stressed from the very beginning the mothers' doing the routine kinds of things accompanied by singing close to the babies' ears, talking, cooing, holding them, trying to get the babies to reach out to them. Some of the babies did reach out to our faces. This began to show us something else. We discovered in two cases that the babies have hearing and, with these, imitation of speech is coming along just fine. With the other babies, we do not yet have this imitation of speech. With Mrs. Rabinowitz, we try very gradually to work some of the infants toward the use of a hearing aid.

An instrument that we use as a visual-auditory feedback monitor is a Loudness Monitor. This was demonstrated to some of you yesterday. It is an instrument with a variety of colored lights and a microphone inside. You can change the intensity of the sound and, as you do, more and more of the color spectrum is lit according to the stimulus. In many areas of auditory training we use a visual stimulus as we try to get children to reach out to hit toys, to move them and the like. For instance, in using the Loudness Monitor, the teachers will hit the drum and get the child to look at the light. Gradually, the child learns to turn toward the light so there is a feedback mechanism working here. Gradually, we are working towards auditory recognition alone, where possible. This training to us visual stimulation with the Loudness Monitor, for example, has also stimulated them in the area of vocalization and babbling.

Once again, the thing we have to be very careful about, of course, is how we use light. We have seen how some of these children will constantly go after light and we need to try to determine how much is natural for the visually impaired child, how much of it is part of a possible language disorder problem. This is a very delicate balance and leads me to recall what Dr. Scholl said the other day -- do we introduce, without knowing it, another handicap to the already handicapped child. This is possibly the most crucial area in working with infants.

Motor Stimulation

Many of the children that we have seen have had little to no motor stimulation. They are just left in their cribs. We help the parents to feel that it is "okay" to pick up the baby, to roll him, to swing him first by holding him close to the body and swinging him out a little bit, then a little bit further. We then introduced the baby swing which is very popular. We try to give the baby a concept of size and of distance by swinging the baby and by swinging things in front of him. For example, a very brightly colored ball or a pacifier and the like is held in front of the baby at a close distance, lit up and then moved back and forth out of their reach hoping that he will follow and reach.

We try to get parents to bicycle the baby; to put him in crawling and creeping positions; to stand in front of him and get him to reach out -- all of this depending on the level of the child's development. We try to get the baby to crawl or creep to a brightly lighted object. Another very basic thing in child development that we have had to suggest to the mothers is simply changing the position of the baby in the crib, prop the baby up, sit him up. Some of the mothers have been afraid, because of the fragile nature of these babies, to let them do anything -- afraid they will fall or bump into something. We must encourage the parents to get the children out of their cribs, to get them to move. If they can start to crawl, to creep, and to walk, they will begin to explore. We set up little obstacle courses as babies do begin to walk. We put something in their way and then observe how they manipulate this. Do they bump into it? Do they go around it? This is especially important if they have been fitted with glasses. Then we will teach them how to go around or how to climb under -- all of this in order to make them aware of the many different movements of which their body is capable, such as crunching down to get under a low area or to go through a tunnel or to climb up a ladder to a baby slide.

With the extremely young infants we had to warn the mothers to be careful about side orientation. We observed many of the mothers would both present the bottle and take it away from the same side at all times, and we instructed these mothers to shift the bottle to the other side to get the baby to turn, to orient himself to a different approach.

There are many variables, individualized approaches, modifications and the like with each infant and within the use of the few procedures I have briefly sketched in these few minutes. We have many additional procedures and observations, but I'm going to conclude here because I feel that it is through your questions, reactions, shared experiences, that we will gain the mutual knowledge we are seeking in this Conference.

The New York Institute Program

Miss Janet Visconti, Director, Rubella Program
New York Institute for the Education of the Blind

The Rubella Program at the New York Institute for the Education of the Blind is a day and resident program and consists of twenty-six children and twenty-six staff members. As you can see, the ratio is an exceptionally good one. We are fortunate at this time to have seven full-time teachers; one speech therapist; fifteen aids; and, three housemothers (1 day: 2 night). This alone is responsible for much of our success.

Let me begin with the initial admission of a child. Our children come to us largely through hospital and agency referrals. Only a small part come from private referrals. When a child is referred to us, an interview is arranged and the child and both parents (if possible) are asked to attend. At this time, the family has a chance to observe the unit in action and we have a chance to become acquainted with the child. Many staff members visit with the child and his family and it is their composite opinion that determines whether or not a child is accepted into our program.

When a child comes to us, the first three weeks are devoted to adjusting to a new and totally strange environment. We try to initiate changes in the child's habits very slowly in order not to make the adjustment any more difficult. This is a period of learning for us, too, as it enables us to observe the child first hand and to discover his capabilities. Once this is done, we know where we should begin to concentrate our efforts.

Each child is assigned to a classroom group that includes: one teacher; three aids; and, three to four children. In most cases, a child is handled by these same people throughout the day, making it necessary for the child to adjust to just a small group of people at first. Once a child has made this adjustment (and most are able to do so in three weeks), we begin work on those areas that we feel need the most concentration. For the majority of our children, this area is daily living skills. Daily living skills include all those tasks that lead to a child's development of self-sufficiency. We concentrate mainly on: toilet training, eating, dressing and undressing, and sleeping. As we all know, toilet training presents the biggest problem, but we have had some reasonable amounts of success in this area. At the present time, out of twenty-six children, ten are completely toilet trained; ten are toilet trained to the point of asking to go to the bathroom when necessary; and, the remaining six are still wetting sporadically both day and night. I would have to say that the single most important factor in toilet training is the establishment of a routine. A child must be presented with numerous opportunities to use the bathroom and those opportunities must be consistent day after day, until the child begins to anticipate them. When this occurs, toilet training has begun. Encourage the child to make his needs known in whatever way possible, at first. This can then be refined at a later date. The important thing, then, is the establishment of a consistent routine and the need to make this routine a part of the child's life. Without this, toilet training becomes impossible.

The next most difficult area to deal with is eating. Upon admission, most of our children are not eating solid food and are drinking from bottles. We do not allow a child to keep a bottle but, rather, introduce a cup immediately, and it is surprising how quickly most children are able to grasp this concept. The change-over from baby food to solid food is far more difficult and takes any where from three to four months to accomplish. We introduce food to our children in what we refer to as "junior food" consistency; that is, meat and vegetables chopped into small, mouthsize bites. We ask that a child sample some of each portion on his plate, but we do not insist at first that he finish everything. At the same time, we try to develop good table manners. Most children can manage nicely with a spoon and shallow bowl and, when this is mastered, we introduce a fork and dinner plate. This technique takes quite a bit of time and only eight of our children are now eating with a fork. The greatest deterrent we have found is the failure of most parents to carry this routine through when the child is home for the weekend. As a result, there is much backsliding and many children will refuse to eat, hoping that we, too, will give in to them.

The area of dressing and undressing is not too difficult for most of our children to grasp. If a child appears to have no knowledge in this area, we begin by teaching him to undress first, as this seems easiest. Teaching a child to dress and undress can be a frustrating experience, but we have found the use of dolls and the Montessori frames to be very helpful. It is a slow process to be sure and, again, cooperation from the family is vital. Learning to button, tie, lace, snap, hook, and pull up and down, are all concepts that should be taught individually. When a child has mastered one, he may move on. Of course, all the above concepts should be taught beginning with the easiest and progressing up to the most difficult.

The sleeping habits of most of our children are good when they enter the program. One problem we have been faced with occasionally is that some children will sleep all day and remain awake all night. This is due, in large part, to parents allowing a child to sleep whenever he wishes instead of establishing a sleeping pattern for him. We have found, though, that once a child becomes accustomed to our routine, he was able to adjust his sleeping habits accordingly. If a child is sleeping in a crib when he enters the program, we do not change this habit for the first three weeks. We feel that enough new demands are being made on the child at this time and to disrupt his sleeping pattern in any way would be unnecessary at first. After a period of adjustment, we introduce the child to a youth bed at nap time. This procedure is carried out for about a week before the child is introduced to a youth bed in the evenings also. At the present time, twenty-four of our children are sleeping in youth beds and the remaining two are sleeping in cribs because of orthopedic problems. In order to make this changeover successfully, the child must feel secure in his new sleeping arrangement. When we first introduce the youth bed, a staff member will sit by the bed with the child until he is asleep. I realize, however, that our large staff allows for this kind of attention whereas a smaller staff could not assign one member just to sit with a child while he is sleeping. However, since we deal with children on a twenty-four hour basis, their sleeping habits are of vital importance to us and seemed to warrant this type of expenditure of staff time. This adjustment, on the whole, seemed the easiest for our children to make.

It is important to note that all of the above areas were not worked on in isolation but, rather, were incorporated into the day's activities, thereby giving the child repeated exposure in all of these areas.

Once daily living skills have been mastered, academic work begins in the classroom. Each child has an individual program designed to meet his needs and to make the best use of his abilities. A child starts on a nursery or pre-kindergarten level and works from there. Of course, there are no time limits on development as each child is allowed to progress at his own rate. Most children begin with the basic academic skills such as: identification of form; shape discrimination; color discrimination; figure-ground activities, and tasks that develop eye-hand coordination. At this time, the development and lengthening of attention span is of the utmost importance. All of the above activities contribute to the establishment of a good attention span. The materials used to develop these concepts are often teacher made, but we have had success with many of the kindergarten materials that are presently on the market. I'm sure that you are familiar with them and the companies (Playskool, Childcraft, Creative Playthings, to name a few) who manufacture them. As a child progresses, he moves on to activities of greater difficulty, and here we have relied upon existing kindergarten and first grade programs as guides for our classroom procedures. Of course, these programs are modified to suit the needs of our children, but we have found them of invaluable assistance. From this point on, we try to develop programs for our children that allow them to function in larger classroom groups, where they will be called upon to work independently in many areas.

That is a somewhat brief picture of our program as it exists today. I need not say that change is the order of the day and, as we continue to see new children with different needs, our program must adapt itself. One of the most valuable assets we have is our staff. They are a group of people whose endless patience, creativity, determination and skill, have made our program work. Without them our children would find it difficult to function. I cannot thank them enough for their contribution.

In closing, let me say that we feel our program should simply be a stepping stone for our children. Hopefully, after an adequate trial period, they will be able to function in schools for the blind, the deaf, or in deaf-blind departments. If this is not feasible, then we must recommend other placement for the child. As great as the temptation is to hold on to our children, we feel that in all fairness to the numbers of children that we have yet to serve, that we must let them go when they are ready. If at that point we can say that we have done everything possible for the child, then indeed, our job is done.

Problems of Multi-Handicapped Children in Rural Areas

Miss LaVerne Tupper, Children's Service Consultant
New York State Commission for the Blind and Visually Handicapped

When first given this assignment, I thought there were lots of problems, few resources and fewer solutions. However, in thinking about it I came to the conclusion it was not as simple as that--there are problems but there are also resources to help in solving them and many people who care.

The multiply handicapped blind child is a state and national problem which must be met on the local level. One factor to be considered, however, is the limited number of blind children in residential schools and large school systems, and of blind adults in rehabilitation centers. The actual incidence of blindness is spread thinly throughout the country. New York State is no exception. The actual number of children needing service in areas outside the large cities is low. The number is scattered throughout the counties. Since it is seldom feasible or possible for schools, hospitals, and evaluation centers to have a special teacher or specialist on their staffs to service blind children, staff personnel routinely fill the gaps. This has been a traditional practice in the education and rehabilitation of blind people. Hopefully, it will no longer continue to be so.

A blind preschool child needs to improve his skills of daily living, train his senses, develop language, build confidence in himself and others, learn to get around in his home, school and neighborhood. He should have the right to share and sample opportunities his community offers all children--its nursery schools, playgrounds, day care centers, libraries, and parks. The multiply handicapped blind preschool child is behind the eight ball from the beginning as he needs so many services--doctors, hospitals, operations, prostheses, therapies--and it takes him so long to acquire even the basic skills of speech, mobility and self-help. He needs individual help and later, group experience. His family needs support. However, he and his family do not live in a vacuum but in a community and, although his immediate environment may not have what he needs, such services may be obtained by going to them. In rural New York State, this may lead to considerable travel.

Today, as a result of the 1963-65 epidemic of Rubella, and for other often unexplainable reasons, we are seeing more blind children who are multiply handicapped. We are not seeing "just blind" children. This multiplicity of handicaps seems to aid in early identification. Even if the child is born in a remote rural area, he is soon being seen and treated at a medical center, where he and his family may be examined by a team of specialists. As a result, the child is not labeled with this or that disorder but as a child with multiple impairments, which occur in many combinations. Children from rural areas find their way to the large medical centers of Albany, Schenectady, Utica, Syracuse, Rochester and Buffalo, usually by referral by their family doctor or the public health service. Some of the centers have counseling sessions with the parents and some refer to agencies which provide this service. Strong Memorial Hospital in Rochester is able to refer children with auditory handicaps to the Rochester School for the Deaf Home Demonstration Unit where the mother is instructed how to handle the child, how to use language and how to initiate play activities. In addition to the sessions for observation and demonstrations, the parents are made cognizant of when and where to get hearing aids, glasses and other prostheses. Since parents may have to travel long distances to obtain such a service, they have to be able and willing to do this. It involves a great output of time and energy as well as considerable money and many parents are unable to continue. Thus, the diagnostic process is available but on-going treatment and the implementation of recommendations are often difficult. (Example: Carol, a Rubella baby from Bath, New York, had cataract surgery in Rochester, numerous other hospitalizations there, sessions at the Speech and Hearing Center, the School for the Deaf, evaluation at Children's Hospital, Buffalo, enrollment and attendance at the ARC School in Geneva, and is now attending the School for Multiply Handicapped at the New York Institute for the Education of the Blind.)

Early identification seems to result in multidisciplinary planning. It is just not an agency for the blind which is helpful with the child, it is also the Speech and Hearing Center, ARC, Head Start, a private nursery school, and a Cerebral Palsy Center. Only one of these may be available to parents in the country--and they have to travel for it. Too often the school is the only service. The public schools are willing to accept more children with handicaps and they are willing to reach out for consultant's help and for ancillary services such as can be given by an Association for the Blind or a Cerebral Palsy Center. During this process the Commission Consultant is the catalyst for community action and the advocate for the children.

The Health Department is one resource which reaches out to all families in rural New York State. Many public health nurses have large geographical areas to cover and a large caseload. Nevertheless, they often carry a family with a handicapped child long past the discharge time, giving practical suggestions to aid in the development of the preschool child as well as giving support to the parents. They do their utmost to refer the child to the proper agency for on-going help. Physical restoration and repair are available to the handicapped child through the Health Department.

The County Department of Social Services is another helping agency in Upstate New York. The staff provides casework and counseling which can strengthen a family with a multiply handicapped child. This agency is able to provide transportation, medical aid, evaluations of home situations and referrals to other agencies. If warranted, it will arrange for foster home placement, public assistance, homemaker service, adoption and day care.

Family Service Associations, Catholic Charities, Jewish Community Service, church groups, service clubs and Associations for the Blind, Inc., are generous with their aid to the families and to the consultant. It may take longer to find help in a rural area, but with a thorough search and sometimes the acceptance of the unusual, it can be done.

Day care centers are a prime need in rural areas. It is estimated that 450,000 children need day care in the State. It is questionable whether adequate funds will be available from either Federal or State sources to set up services this year. The Youth Facilities Improvement Act of 1969 removed a barrier to expansion of day care facilities with authorization of 50 million in long-term, low-interest loans for construction, renovation and equipping of non-profit day care centers. It is our belief that day care should be as freely available as the public school and that it should be offered to all children. Day care should be a matter of choice for the parent and there should be ample opportunity for parents to participate fully in the programs.

The emotionally disturbed blind child is still in need of treatment facilities. We do have the Center at Creedmoor State Hospital on Long Island, but that is a long way away from the homes of rural New York children. Also, there is the Center at Fairmount near Syracuse, but its future has not yet been clearly established. If treatment centers, public or private, would take the blind child on the same admission requirements as a sighted child, this would relieve the situation. Running a close second to the goal of acceptance is the adjunct, that once admitted, the child has appropriate service. Psychologists and teachers often say, "They are not able to test, treat and teach a blind child," but once they allow themselves a try, they do very well. Also, their science and skill can be augmented by in-service training and consultations on the specifics of blindness. In this day of rapid change and innovative approaches, new thinking is needed on this whole problem. Dr. Rhodes, Professor of Psychology at the University of Michigan, said, "The time has come to begin to concentrate attention upon changing the ecological conditions under which children have to live and grow, and thus reduce the humber of children who are excluded or alienated from their living units. This is the only way in which our society can hope to come to terms with the magnitude of the problem called emotional disturbance. Certain environments may be unable to accommodate the unfolding nature of childhood. The disturbance attributed to the child may also be reflective of this insufficiency."

The multiply handicapped blind child does not fit easily into established program mainly because each discipline is still inclined to service its own special field. The agencies concerned with the blind, the deaf, the mentally retarded, in their initial thinking often forget the child is a child and should not be categorized into compartments. Luckily, change is coming. The helping professions, the medical personnel, teachers and therapists, are sharing their knowledge of what has been done for the child and his family. Each has a contribution to make with his expertise, not only to the family but to his fellow workers. The team, with the family on the team, achieves goals and satisfactions which a single individual cannot. It is important to reach out to families rather than wait for them to come to you. Coordination and cooperation of agencies in a rural area often take a great deal of leg work, phone work, and going beyond what has been thought of as limits of a particular service. Today, the emphasis is upon meeting the need when the need is present. Different kinds of people are becoming involved--volunteers, para-professionals, and college students. Parents are more prone to explore the services of their community and to seek out those which will help their children.

Federal funds have been made available for Head Start and day care centers in many communities, and the multiply handicapped blind child is welcome in them. One of the rigors of life today is finding a way through the muliplicity of programs--and to match the family with the program. The Board of Cooperative Educational Services, a combination of school districts, is able to provide many services unavailable in a single district. It will offer classes, transportation and specialists which were unattainable a few years ago.

Services to the young visually impaired child and his parents focus upon enabling the child to achieve his greatest potential. His day by day progress may be infinitesimal, but such gains over a period of time enable him to function to the best of his ability in his family and neighborhood. The values of an enriched environment cannot be underestimated.

A consultant's work in rural New York State would be impossible without the help of teachers, nurses, social workers, public and private agencies. Much help has been given to families and to me.

The Impact of Federal Legislation on Education of the Handicapped

Robert Dantona, Coordinator
Centers and Services for Deaf-Blind Children
Bureau of Education for the Handicapped
U.S. Office of Education

How does one go about measuring and evaluating the impact of Federal legislation upon the education of our nation's children and those institutions responsible for educating our handicapped children; training of teachers and other types of specialists; and research aimed at facilitating the education of the handicapped?

How does one even begin to attempt to evaluate the impact on education when a nation which spends $65 billion a year on all levels of education -- nearly as much as the entire rest of the world -- is not satisfied with the results and concerned persons in all walks of life ask: "Are we getting as much out of the dollars we spend as we can?" or "For all its worth, are we giving our children the best education our money can buy?"

We have the means by which we can make our nation's educational institutions second to none in the world. In all levels of education there exist more than 100 Federal Assistance Programs administered by the U.S. Office of Education for construction; programs, instruction, and administration; teacher and other professional training and student assistance; and research. The total educational expenditure for fiscal year 1969 for the Office of Education was $3.5 billion. This represents more than an eightfold increase since 1960, for the category of preschool, elementary and secondary education which, combines with the expenditures of more than 24 other Federal departments and agencies, raises the total government education outlay to $9 billion. However, Federal funds supply only about 8% of national expenditures on elementary and secondary education in public and nonpublic schools. Other sources of funds for education include State support for 38% of school revenues; and, local funds which for the most part come from property taxes and provides 54% of the support for education.

Budgets, whether they be Federal, State or local, serve as a blueprint for the future. They tell us where we have been, where we are going, what our priority needs are and how we plan to meet them. Our system of government provides for the establishment of legislation on a Federal, State, and local level as an instrument by which we can develop programs to effectively meet our established priorities and needs whether they be national, international, State or local.

In the area of education this nation's legislative achievements can make us all proud. In 1965, twenty-five major pieces of legislation to improve the life of the American people were enacted. An incredible achievement by the 89th Congress. Of this legislation, nine were in the area of education. Included were the following Acts which were to have significant influence on the education of the handicapped:

- The Elementary and Secondary Education Act of 1965 (P.O. 89.10)
- National Technical Institute for the Deaf (P.L. 89-36)
- Captioned Films for the Deaf Act (amended P.L. 89-258)
- The Higher Education Act (P.L. 89-329)
- Public Law 98-313, Amended Title I of the Elementary and Secondary Education Act (P.L. 89-10) and authorized grants to State agencies operating or supporting schools for handicapped children.

It was the Elementary and Secondary Education Act of 1965 (P.L. 89-10) authorizing a total expenditure of $1.3 billion for fiscal year 1966, which represented the greatest legislative commitment ever made by the Federal Government to improve elementary and secondary education. This Act was approved April 11, 1965 and on November 1, 1965, Title I of the ESEA was amended by Public Law 89-313 to focus attention on children with physical, mental, or emotional handicaps in schools for the handicapped operated or supported by State agencies.

The Elementary and Secondary Education Act of 1965 has become the instrument by which the needs of handicapped children and those concerned with developing educational services for these children; training manpower; and research to develop and demonstrate new techniques and methods in working with these children would now be heard.

The 1966 Amendments (P.L. 89-750) amended the 1965 Act by adding a new Title, VI-A, which provided for assistance in the education of handicapped children at preschool, elementary and secondary levels. The 1966 Amendments directed the Commissioner of Education to do the following:

1. to establish a National Advisory Committee on Handicapped children
2. to establish and maintain within the Office of Education the Bureau of Education for the Handicapped, which would be the principle agency in the Office of Education for administering and carrying out programs for the handicapped.

The 1967 Amendments (P.L. 90-247) broadened and extended the existing program of services to the handicapped to include the following:

1. Regional Resource Centers (Title VI-B)-- to provide testing and educational evaluation to determine the special education needs of children referred to them; develop educational programs to meet those needs and assist schools and educational agencies in providing such educational programs through consultation, re-examination and re-evaluation, and technical services.
2. Centers and Services for Deaf-Blind Children (Title VI-C)-- the regional centers will provide comprehensive diagnostic and evaluation services; education, adjustment and orientation programs; and consultative services for parents, teachers and others working with the deaf-blind.

3. Recruitment of Personnel and Information on Education of the Handicapped (Title VI-D)--to improve dissemination of information concerning educational opportunities for the handicapped.

The existing Instructional Media Program was expanded to make educational media services available to all types of handicapped persons, their parents, employers and others involved in the education or training of Handicapped persons.

Public Law 90-247 also amended Title III of the Elementary and Secondary Education Act and earmarked not less than 15% of these funds to be used for the handicapped starting fiscal year 1969. This law also provided for full funding under Title I for educational activities for children in State-operated or supported institutions for the handicapped.

The establishment of the Bureau of Education for the Handicapped under the 1966 Amendment to the Elementary and Secondary Education Act, is a milestone in the history of the education of handicapped children. For the first time, Federal legislation provided for the establishment of an instrument to speak for the education of handicapped children. The Bureau provided a voice in behalf of the handicapped with the assistance of the States to develop the priorities and needs of the nation's handicapped. Federal support for programs administered by the Bureau in -- Research, Training, and Educational Services has grown from $53 million in fiscal year 1968, to $85,850,000 in fiscal year 1970. Hopefully, this rising Federal commitment will continue.

What impact has the legislation for the education of the handicapped administered by the Bureau had on the nation's estimated 7 million preschool and school age handicapped children? It is estimated that only 2.5 million of the nation's handicapped children needing educational services are presently receiving special education to meet their needs. In fiscal year 1969, the combined project expenditures of Title I and Title VI-A of the Elementary and Secondary Education Act, totaled $51.2 million and provided services for approximately 224,758 handicapped children.

How does one assess the value and impact of such programs on the lives of the children involved, their parents, and those who are instrumental in the operation of such programs? Surely these programs and the efforts expended by those involved made some difference in the lives of all those concerned. If this were not the case, there would be little justification for the continuation of Federal as well as State and local efforts to provide vitally needed programs and services for the nation's handicapped children.

On April 13, 1970, Public Law 91-230 was enacted. This Act extended all major programs of assistance for elementary and secondary education for three years, through fiscal year 1973. Of particular importance to us in this Act, is the change affected in Title VI, which now codifies all existing legislation pertaining to the education of the handicapped into a single Education of the Handicapped Act. The Act also authorizes a new program to educate children with specific learning disabilities, authorizing $20 million for fiscal year 1971.

Part C of this new Act (P.L. 91-230) brings together the legislation to establish Centers and services to meet special needs of the handicapped. These include:

- Regional Resource Centers (Sec. 621)
- Centers & Services for Deaf-Blind Children (Sec. 622)
- Early Education for Handicapped Children (Sec. 623)
- Research, innovation, training and dissemination activities connected with centers and services for handicapped (Sec. 624)

Our greatest hope for providing vitally needed services for the handicapped rests on Part C of this Act and Part B which provides grants to the States for the purpose of assisting them in the initiation, expansion, and improvement of programs and projects for the education of handicapped children at the preschool, elementary school, and secondary school levels. Part B is the former Title VI-A of the Elementary and Secondary Education Act. For fiscal year 1971 Congress authorized for Parts B and C, a total of: $236,500,000. Compare this sum if you will with the actual total budget request by the Bureau for the Education of the Handicapped in fiscal year 1971: $95,000,000. It is significant to note that the House approved budget allowed for an additional $10 million increase, raising the total budget to $105 million for fiscal year 1971.

And now I must ask you to return to a statement I made earlier. "Budgets, whether they be Federal, State or local, serve as a blueprint for the future. They tell us where we have been, where we are going, what our needs and priorities are, and how we plan to meet them."

The responsibility for the welfare, education and health of our handicapped children falls upon all of us--Federal, State, and local agencies alike. To provide services for all the nation's handicapped children is often thought to be an impossible dream. With all our great resources as a nation, with all our skills and know how, can we accept the knowledge that more than 60% of our handicapped children are <u>not</u> receiving needed educational services?

We have the mechanism, an instrument if you will, in the form of Federal and State legislation, in the form of human resources and facilities to deliver services, to close the gap between those handicapped children being served and the majority waiting to be served. It is not a matter of money alone as the solution to all our problems--what matters is how effectively we use it. How do we plan for and determine the needs of our children and the programs required to meet their needs. It is not legislation alone that has an impact on the education of handicapped children. It is our collective efforts that can make an affirmative impact. It is the combined effort--State, local, and Federal that makes the difference--in changing the lives of the children and their parents with whom we are concerned.

For 18 months I have had the responsibility to establish Centers and Services for Deaf-Blind Children in the U.S. The authority to establish such programs comes from P.L. 90-247, Part C, which amends

Title VI of the Elementary and Secondary Education Act. The need for such a law and Congress' final approval of this law grew out of the 1964-65 Rubella epidemic which afflicted some 20-30,000 children with a variety of disabilities. In September 1968, Congress appropriated $1,000,000 to establish Centers to provide vitally needed diagnostic and evaluative services; programs in education, orientation and adjustment; and, consultative services for parents, educators and others working with deaf-blind children.

It is estimated that as a result of the Rubella epidemic in 1964-65, some 4,000--5,000 deaf-blind children may now exist. Prior to this sudden increase of deaf-blind children, existing residential educational programs for deaf-blind children (seven in all) provided services for less than 100 such children in the United States. Even prior to the Rubella epidemic, services were urgently needed for some 500 deaf-blind children who for the most part either remained at home, or were institutionalized. Now, after the Rubella crisis, what hope could there possibly be for providing services and meeting the needs of several thousand of these children who have now reached school age?

One million dollars of Federal funds to help Rubella deaf-blind children is not the answer to the total problem. The law and the money appropriated, is only an instrument out of which grew a system to coordinate existing and potential resources with the cooperation and participation of State and local agencies to meet a crisis situation. Using Title VI-C funds, ten Regional Deaf-Blind Center systems, based upon the cooperative agreements by States participating in this program, have been established in order to meet the increasing demand for services to deaf-blind children placed on them.

The cooperation demonstrated by State Departments of Education, Public Health, Commissions for the Blind, Department of Institutions and others, has been overwhelming. The desire of public and private agencies to provide related services such as medical, clinical, educational, social, and counseling has also been most gratifying. There has truly been a national response and a national commitment demonstrated at a Federal, State and local level to develop new resources, or to expand existing resources to include services for the deaf-blind child.

Surveys performed by the Regional Centers, with the cooperation of State and other agencies have identified nearly 2,500 deaf-blind children. Most of the Centers are still compiling data and it is expected that the total of deaf-blind population uncovered will be around 4,000-5,000. Most of these children, as already indicated, are by-products of the 1964-65 Rubella epidemic and are now approaching school age.

We know that of the 2,500 children identified, some 802 are receiving the benefit of an educational program in residential and/or day school programs, both public and private. Some 347 children are known to be in institutions for the retarded. Plans are underway now to develop in-service programs for the staff in these institutions so that something more than a "custodial" program may be available for the deaf-blind children who can benefit from such a program. A national effort is also underway to provide comprehensive diagnostic services including educational evaluation, of all known or suspected deaf-blind children.

The population of deaf-blind children not receiving services is still very great. The challenge that lies before us is even greater. Federal support has increased from $1 million in fiscal year 1969, to $2 million in fiscal year 1970. With these additional funds, two new planning Centers were funded and will start in June 1970. Increased support for the operation of eight other Centers started in June 1969 will make more services available to greater numbers of deaf-blind children in the nation.

We have the resources to meet the challenge--the real question and the greater challenge to all of us is whether we have the will--to persevere and to overcome all obstacles which prevent us from meeting our responsibility to these handicapped children.

I am confident that those of you here today, concerned with the needs of deaf-blind children have this will--and I know that together, we will all meet our responsibility.