REPORT RESUMES

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AAIB NATIONAL CONFERENCE ON PRE-SCHOOL SERVICES FOR VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES. (ST. LOUIS, MARCH 28-30, 1965).
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THESE 11 PAPERS WERE PRESENTED AT THE AMERICAN ASSOCIATION OF INSTRUCTORS OF THE BLIND NATIONAL CONFERENCE ON PRESCHOOL SERVICES FOR VISUALLY HANDICAPPED CHILDREN AND THEIR FAMILIES. PHYSICIANS, SOCIAL WORKERS, EDUCATORS, AND REPRESENTATIVES OF COMMUNITY SERVICES PARTICIPATED IN THE CONFERENCE HELD MARCH 28-30, 1965. IN THE KEYNOTE ADDRESS, ELIZABETH MALONEY SPOKE ON "WHAT ARE WE DOING AND WHAT CAN WE DO FOR VISUALLY HANDICAPPED PRESCHOOL CHILDREN." OTHER PAPERS PRESENTED WERE--(1) "METHODS USED IN DEFINING BLIND CHILDREN IN GREATER CLEVELAND" BY PATRICIA STONE, (2) "IDENTIFICATION AND EVALUATION OF INFANTS AND CHILDREN WITH VISUAL DEFECTS--THE ROLE OF THE PEDIATRICIAN" BY GORDON BLOOMBERG, (3) "THE IDENTIFICATION, DIAGNOSIS AND EVALUATION OF EYE DISEASES" BY PHILLIP SHAHAN, (4) "IDENTIFICATION, DIAGNOSIS AND EVALUATION" BY ROBERT MCGUIE, (5) "COUNSELING WITH PARENTS OF BLIND CHILDREN--A SOCIAL WORKER'S POINT OF VIEW" BY MARIE MORRISON, (6) "SOME THOUGHTS ON THE EMOTIONAL DEVELOPMENT OF PRESCHOOL CHILDREN" BY THOMAS BRUGGER, (7) "CHILDREN'S BUREAU HEALTH SERVICES FOR CHILDREN WITH VISUAL HANDICAPS" BY ALICE CHENOWETH, (8) "REFERRAL TO AND USE OF COMMUNITY RESOURCES" BY ROY DAVIDSON, (9) "WHAT AFFECTS BLIND CHILDREN'S DEVELOPMENT" BY MIRIAM NORRIS, AND (10) "LIAISON WITH AND REPORTING TO SCHOOLS" BY RANDALL HARLEY. (MY)

AAIB NATIONAL CONFERENCE ON PRE-SCHOOL SERVICES for Visually Handicapped Children and Their Families

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American Association of Instructors of the Blind
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KEYNOTE ADDRESS

WHAT ARE WE DOING AND WHAT CAN WE DO FOR VISUALLY HANDICAPPED PRE-SCHOOL

By Miss Elizabeth Maloney, A.C.S.W.
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As recently as 1907 a publication* intended for parents and professional workers stated --

> "A blind baby should have special care from birth or from the very day it loses its eyesight. That special care can be furnish only in an institution especially established to give such care -- an institution provided with the best doctors to give orders to the best graduate nurses for the physical development of this child; the best trained teachers to give instructions to the best trained helpers for the mental development; an institution full of the home spirit, for the blind child who needs closer care than a baby who sees. The blind baby must have constant attentio skilled attention during all its waking hours.
>
> No matter how superior its home surroundings may be, the baby should be taken to an institution specially provided for its care. It must have the undivided and constant attention of traine workers, the companionship of other children and the care given daily by physicians who are child specialists."

This was typical of the sociological climate of that time. Services to children were primarily protective with society seeing its concern as providing for the orphan or the abused child. All child care was provided through orphan asylums, some of which remain until this day, at least in name.

However, the 1900's have seen a new and dramatic development of understanding and concern for the individual and respect for him as a person of unique human worth. Work for the blind, too, has seen this change and services today are far different than they were 50 years ago or indeed as they were within my own remembrance of 20 years. Twenty years ago there was little blindness in children, but even then the dark shadow of RLF was evident and the tremendous attack of the condition was fast approaching.

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*"The Baby Blind" or "Keys that Unlock Souls After Normal Physical Life Has Been Established," by Cynthia Westover Alden.

Services to blind children were pitifully few and widely separated geographically. Because of the infrequent incidence of blindness, services to blind children existed primarily in highly institutional patterns. In the field of services for handicapped children, it was the parents, in almost every instance, who joined together to demand a better and more productive life for their children. It was in response to their cry for help that organizations such as those represented here today established special services for blind childre
It was from these same parents that workers learned so much about the individual blind child and his needs. Many professional persons became involved in service to blind children principally from the professions of psychology, education and social work. The contributions of parents to these professions cannot be measured, but it must surely be acknowledged. Today, blindness has again become, numerically, a rare handicap and again the parents of blind children are found at widely separated geographical points. It is very exciting to see, however, that a conference such as this permits the voice of the parents to be heard, in force, as they continue to seek solutions to their individual problems.

One concept in work with persons who are blind has become the foundation upon which service is now developed. It is simply this. If we look at the blind person, vertically, we will see only his blindness; if you look at the person who is blind, horizontally, we will see the whole individual in whose life blindness is just one characteristic. The truth of this statement is immediately apparent, its wisdom and depth become more important with each new experience.

The child who is blind, then, is essentially a child, to be loved, understood, educated and, finally, emancipated. Yet this child differs from the average youngster and it is a difference greater than color of eyes or hair or skin. If he is totally blind, his difference is perhaps easier to recognize intellectually and perhaps harder to reconcile emotionally. When the child is visually impaired but has some remaining sight, blindness is much more difficult to understand intellectually, but perhaps not quite as traumatic emotionally. There is a finality to total blindness which parents must recognize. Partial sight, on the other hand, is a frequently unknown quantity giving the parent hope that some new and advanced technique, some doctor, some new lens may restore their child to normal vision. In the presence of partial sight, an occasional parent may deny that his child is blind and may insist that his child measure up to the full expectations for a sighted child without any of the adaptations his limited vision demands. In either case, however, the knowledge that the child is imperfect is probably the most difficult single emotional problem that a parent ever has to face within his own emotional structure. It is the universally found feelings of frustration, of failure and guilt that is the first problem of the parents. Facing the existence of blindness is an experience for both parents. In the average family, however, there is and needs to be a distinct difference in role between the mother and father. This difference in role as well as the usual difference in reacting to emotional stress as between man and woman results in some heightening of the parents' problems in a time of crisi The mother of a young child is normally concerned with the small but intense experiences of everyday living. Her activities are usually tightly constricted because of her home and family demands. She is alone except for young children much of the time. Feelings may well be intensified. The father, on the other hand, is usually a part of a wider adult world, at least for the working day, and his job demands may, momentarily, take his mind off his feelings. In addition, men are not as apt to admit negative feelings or to discuss them. All too frequently we see the mother becoming the central person in receiving counseling services so desparately needed by both parents. We almost deny the father's need for help because he is less accessible and less verbal, yet I am sure that his need for individual personal counseling is just as real and just as great. Without such help he is frequently unable to communicate to the mother his sharing of concern. Without help he is apt to carry unresolved emotional difficulties in his heart and in his mind only to have these problems come to the fore with increased intensity at a later stage of his child's development. How best to help both parents then remains an important concern. Beyond their own feelings, parents of blind children are extremely vulnerable to the authoritarian forces in their families and communities When a child is blind at birth or becomes blind early in life, parents face a special role for which no one ever prepared or trained them. In addition to the complete lack of knowledge about how to cope with the problem of blindness, they may be faced with a strangely unresponsive infant who seems, at times, to defy their best efforts to care for it. Mrs. Burlinghame of the famous Anna Freud Clinic in England, has been studying parent-child responses in situations where the child was born blind. She has pointed out the tremendous role that sight plays in establishing a climate of comfort and love between parent and child. Conversely, she points out how the absence of sight brings about a surfa failure of response on the part of the child and how this failure of response can set off a vicious cycle within the emotional area. Faced with a feeling of inadequacy about how to best rear their child, the parents of the blind child turn to family, friends and community for help. It is common experience for us to be told of the varied and conflicting advice given -- some of it good, much of it terrible, a great deal of it highly subjective. The parents are face with the task of applying this advice to their child. We hear, too, a frequent negative reaction to the fact that the birth of a blind child places the family in the position of having to become the clien of a community social agency. The old, old view of the "charity" dispensing social worker is still very much a part of our society. Most of us think that approaching a social agency for help means a giving up of our dignity and becoming dependent on others. The simpl fact that this is not true does not dispel the image and does not alt the negative feelings of most parents as they first come for help. The problem of changing this public image and the need to reach more of those persons needing counseling help is a very serious one which may well concern the professional and the parent alike.

During the preschool years, in particular, there is one rather crucial time for the parents. The initial painful knowledge that one's child is blind is re-awakened when the youngster begins to exhibit active curiosity about the environment. The parents again are exposed to a wider circle of people in the supermarket, in church, in the park, at the zoo. The blind child draws attention and sometimes comment. We know the child's need for the stimulation of this broader environment. Do we give the parents the kind of emotional help they need as they, too, are exposed to it?

Much of the service that is available for the blind child is entirely child-centered. In stating this as a problem I am not for one minute denying the extreme importance of services for the child himself, but I am pleading for resources that will provide assistance for the parents as well. It is within the family unit that the child's personality will be formed, his values will be established, his strengths will be enhanced and his weaknesses overcome. It is, therefore, most essential that the family unit itself become the center of concern and that methods be provided for assisting families to function constructively for the benefit of all their children, including their blind child. To provide services to the child alone may, at best, improve the child at the cost of isolation from his natural environment and, at worst, antagonize a family towards the whole community and even to the child.

There are, however, problems specific to the blind child. The most common perhaps is inadequate understanding of his environment. Today we are bombarded with visual stimulation in every conceivable area. The sighted child is being educated during almost every waking minute by visual means, consciously or unconsciously. The blind or partially seeing child lacks this basic knowledge. Then, too, every blind child is over-protected to some degree. Not knowing what or how much he can achieve, we all pretty much protect him from some area of experience, either physical or emotional, or both.

Frankly, much of the problem faced by the child who is blind is that he must cope constantly with reactions to him - not as a child - but as being blind, and much of parents' problems is that they must cope constantly not just as parents, but as parents of a blind child. The blind child is sometimes damaged by failure of parental understanding of his needs. He is also sometimes damaged by failure in understanding on the part of teachers, social workers and psychologists. All of us are individuals with our own kinds of solutions to the problems of life. These methods of solution will unquestionably determine our behavior and our response to the child. We may, as parents or professional workers, bring either too much pressure or too little pressure to bear on the child. We may be using a measuring stick that will not apply to the child in question, a measuring stick too often created out of our own personal needs and not related to the child. We are reacting to blindness and not to the child. The blind child may be facing proble stemming from a second handicap such as retardation or brain damage. The blind child may be adversely affected by limitations in his community which prevent his getting the kinds of help to which he is entitled.

You will be meeting for the next two days to try to develop some new insights so as to cope with some of these problems that beset the parents and the child. You will hear again and again that there is no one easy solution. Each family-child-community complex is uniquely different. If there can be said to be one priceless ingredient that we need for ourselves and that we hope to give to our children, it could be embodied in one word, identity. Webster defines identity as: 1. sameness of essential character and 2. unity and persistence of personality; individuality. A boy of seven defined it for me in a way that I liked better. I remarked how much he looked like his father. He replied, "Some people say I look like my father and others say I am just like my mother...but all I want is to look like myself." The single most pressing need of the blind child and of his parents is one of identity and it is a need that has many facets.

One goal common to all of us here is to provide children with a sufficient core of individuality that they are distinct persons capable of decisions and of action, able to manage in life without undue dependency on any one person, capable of positive morality, able to form satisfying relationships with others, convinced about their own dignity able to accept their differences and able to hold themselves and others in respect. This is being a person, an identity.

The child who at age five says, "Johnny wants a drink of water" or, "You want a drink of water" instead of "I want a drink of water," has not achieved individual identity. The child who says at age ten or twelve, "I don't know, ask my mother" instead of either "Yes" or "No" or, "I will ask my mother," still lacks individual identity in some area. The child who at age eighteen is without any goal or even without any idea of vocational possibilities still lacks identity. These examples are over-simplifications. They are descriptions that explain identity. Over the centuries there has been a continuing effort on the part of philosophers to explain being - existence - identity. The words, "know thyself" in the time of Socrates, the "I think, therefore, I am" of Descartes, are all part of man's search for answers about himself and his relationships within the universe.

Psychologists tell us that our personality is made up of a series of cycles, each one of which complements the others and all of which, functioning together in harmony, create a healthy personality. They define these cycles or stages as conition, cognition and affection. When a child fails to develop some one of these cycles, one aspect of personality functioning is absent and some failure of identity must occur. This holds true of any child. The normal sighted child develops these psychological abilities a little at a time, adding by constant experience. The blind child may not have equal opportunity for experiences which will increase his knowledge and, in addition, may form restrictive patterns of functioning because of negative associations or because of constant reinforcement of negative values. Another aspect of identity for the blind child is one which is in some ways rather controversial. There has been so much emphasis on the integration of the blind child into his sighted community that we have at times denied that there exists a blind community as well. Now it is true that the blind child is more like than unlike all children. In this sense and because of his basic childliness, to coin a word, he must have experiences which will help him to relate to and to be integrated into the community of sighted children. However, in one important aspect of his functioning, the blind child is different from other children. He must learn to be comfortable as a blind person as well as a blind person among sighted persons. It is only as one become able to live with blindness as an essential part of one's personality that one can become comfortable in associations, with either blind or sighted groups. It is also this comfortable status with blindness that enables the blind person to create the climate of acceptance in sighted groups. As one is at ease with himself and with his difference, his energies are freed to be concerned with other people and events and it is this concern which truly permits communication.

How, then, can we give the child this dual experience of both sighted and blind associations in the right proportion and at the right time or times? I am convinced that programs which maintain the blind child in association with sighted children only, throughout the entire process of growing up, are no more realistic than programs which maintain the blind child in association with blind children. I do not know that there is any one answer for all children.

Identity does not come about through growth experiences alone. The child's identity is an emotional transfer as well, coming to him from parents, teachers, group leaders and from other children. It comes through identification with feelings of parents and others in positions of importance in the life of the blind child. Because this important self does reflect so strongly the feelings of parents and teachers and others, let us be concerned with identity for parents, teachers, and social workers. It is not fair that the mother of a blind child must become an early Christian martyr for her child. Rather, she must be helped to maintain her own youth and vital personality, her enjoyment of life. She has the right to the continued development of her own personality. She has the right to have occasionally very negative feelings about her child without extreme guilt. Parents need the strength to challenge the status quo - to seek out new resources without fear that they will damage the services they presently receive. They have to be free to try new approaches and new methods. They have to be free, also, to question the professional quality of the services they do receive and free to demand service of the highest possible professional quality.

To give the parents this right to their own identity imposes on the professional worker a special role of identity within the concept of the profession. It is the need to accept and respect and understand the parent as a parent. It is the further need to consistently reevaluate his own service and to be ready to suggest new areas of help, if these are indicated. Truly professional help does not tie parents t it, does not demand loyalty or gratitude or adherence to one preferred plan. It is the first to seek out new and daring solutions. There is no one overall solution to the problems of adequate service for the child who is blind. Each community, each family, each professional worker, whatever their discipline, must maintain an open mind so as to be able to use creatively whatever help is available.

METHODS USED IN DEFINING BLIND CHILDREN IN GREATER CLEVELAND

by Patricia Stone, Coordinator
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To accurately establish the number of blind children in a given area, especially in the pre-school age group, is very difficult. This is doubly true when a state has no law requiring compulsary registration of blind persons. Ophthalmologists and pediatricians are key people in maintaining an up-to-date register of blind children, yet these physicians oftentimes may be reluctant to report blindness in a child, even though he appears to have a severe visual loss. This is due in part to the difficulty involved in examining a young child, and the uncertainty of obtaining an accurate visual acuity. This reluctance may also stem from the awareness, on the part of the physician, of the emotional shock to the parents of such a diagnosis. He may wish to spare the parents as long and as much as possible. In spite of the foregoing facts, however, ophthalmologists and pediatricians were the chief referral sources of the pre-school age blind children during the study phase of The Project to Benefit Blind Children in Cleveland, Ohio.

An influencial ophthalmologist and a well known pediatrician were members of the steering committee which guided this project. The power structure invested in this committee was the most effective means of defining blind children in Greater Cleveland while the project was going on. A wide range of social agencies and community organizations were represented on this committee. In addition to the ophthalmologist and pediatrician referred to above, there were the director and assistant director of the Health Council of the Welfare Federation; the executive director of the Jewish Children's Bureau;

the president of the board of trustees of the Cleveland Society for the Blind; the director of nurses of the County Board of Health; the director of special education of the Cleveland Board of Education; the executive secretary of the Day Nursery Association; the supervisor of Children's Services of the State Welfare Department's Division of Services for the Blind; the acting chief of this same state agency; the executive director of the Cleveland Society for the Blind; the supervisor of nurses of the Maternal and Child Health Association; the director of Children's Services; the executive secretary of the Crippled Children's Association; the director of the Family Service Association and the chief supervisor of social work of the Crippled Children's Association. The ophthalmologist and pediatrician on the Steering Committee were also instructors in schools of medicine. In this dual capacity of practitioner and teache they proved very valuable in learning about and referring blind children.

We have established a policy of sending letters of appreciation to members of the Steering Committee whenever we receive from them the referral of a new blind child. In these letters we stress the importance of the service they have rendered in making such a referral. Another factor contributing to our success in locating children with visual impairments has been the frequent opportunities we have been given to appear before groups for the purpose of interpreting blindness, in its many aspects. During such interchanges, many myths are refuted and fact is separated from fantasy.

Nurses, in all areas of the nursing profession, have been a very fruitful source for us in learning of very young blind children.

Public Health nurses, school nurses, the visiting nurses and clinic and hospital nurses have all given us their full cooperation in contacting us as soon as they know of a blind child in their area. In a one week period we were given the names of three children, all under two years of age, by Public Health nurses. And, just recently, after speaking to a group of student nurses from a clinic in pediatrics three blind babies were referred, all under six months of age.

A seminar was conducted at the Day Nursery Association for the purpose of stressing the importance of integrating blind children into nursery schools with sighted children. A high per cent of Cleveland's nursery school teachers were present. The film "Toward Tomorrow" was shown and literature was dispensed. Four teachers who had been successful in accepting blind children into their classes gave an account of some of their experiences. A question and answer period followed. As a result of this conference, we received referrals of blind children from three nursery school teachers.

In Greater Cleveland there are two very active organizations composed of parents of blind children. Many referrals have been received from these groups. We are invited to attend their meetings frequently, and we, in turn, refer to them the names of new parents of blind youngsters. When we make our initial contact with these new parents and tell them of community resources available to them, mention is always made of their membership to the parent organizations. We have heard repeatedly of the benefit derived from membership in these groups.

We have received several referrals of pre-school youngsters from the

Division of Services to the Blind of the Welfare Department. This agency attempts to keep a register of blind children throughout the state of Ohio. We, in turn, send copies of all new eye reports received on blind children to the State Services for the Blind. We have a documented eye report in our files on all blind children in Greater Cleveland which substantiates their blindness.

We have had opportunities to speak to church and religious groups during the time the project has been in progress. We have been called upon to help orient Sunday School and vacation Bible school leaders preparatory to their acceptance of blind children into their groups. This has resulted in a few referrals of blind children not known to us before. In most instances the referrals have come from the clergy.

The smallest number of referrals in the pre-school age group, has come from local social and community organizations. Two youngsters in foster homes sponsored by the Child Welfare Department were identified and one child known to Children's Services was identified by this agency.

We have mailed out questionnaires to parents when the name of a child has been referred to us with no accompanying eye report to verify his legal blindness. The response to these questionnaires has been quite favorable.

In the school age group, our largest referral source has been boards of education. In Cleveland there are two types of special classes for children with a visual impairment--braille classes for youngsters with a visual acuity in the range 20/200 to total blindness, and sight saving classes for children with a visual acuity in the range from 20/200 to 20/70. We have concluded from our experience in the project that there is an untapped resource in the sight-saving classes. Only last week we learned of the names of thirty-one legally blind children enrolled in sight-saving classes with a visual acuity of 20/200 who had never been registered with us. We know that if this is true in the classes in Cleveland, it must also be true in the sight-saving classes in the suburbs.

It may be of interest to note here that in 1960, when the project was initiated, there were 71 blind children registered with the Cleveland Society for the Blind. When the study phase of the project ended in May, 1964, 197 children were registered. Now, one year later, while the project is in the process of offering a demonstration service program to blind youngsters, there are 271 children registered with us. They range in age from six weeks to 18 years.

We are firmly convinced that referrals increase when a concrete service program for blind children is established in a community. We are further convinced that this program must be a needed one and a joint community effort if an accurate count of the blind child population is to be taken. And, finally, we are certain that if we have a worthwhile service to offer blind children and their parents, and if we make this service known, our referrals will continue to increase.

One of our most cooperative ophthalmologists and the one who has worked very closely with us in our effort to define blind children never fails to put at the bottom of each eye report he sends to us on a new-found child, "Please do <u>all</u> you can for this youngster."

IDENTIFICATION AND EVALUATION OF INFANTS AND CHILDREN WITH VISUAL DEFECT: The Role of the Pediatrician

by Gordon Bloomberg, Pediatrician
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INTRODUCTION

The role of the pediatrician in identifying and evaluating the infant or child with a visual defect is twofold. He is often first, especially in the infant, in the position to recognize the problem, and secondly, he must care for the child as a whole. This last is of special importance lest we forget that we are always dealing with a child whose visual problem may be only part of his symptom complex, organic or psychological.

Vision is so intimately identified with the whole child that we cannot fully comprehend the significance until we investigate the whole child. For this reason, even minor defects in the function of vision have importance for the pediatrician as well as for the ocular specialist. It is the grave defects of blindness and near blindness that reveal the significance of visual perception in the development of the child.

Part I

Early Normal Development

The period of infancy is an extremely important one since most blindness has its onset prior to one year of age. Knowledge of the normal development of visual acuity helps the pediatrician to distinguish at an early time, deviations from the expected time-table of developing abilities. At birth the eye is relatively functionally and structurally immature. The eye lids are closed most of the time. The eyes are sensitive to light and even when the eye lids are closed the baby will blink in a strong light. By two weeks he is able to look at large objects but does not follow them. At four to five weeks he looks at relatively small objects and will follow bright objects. By eight to ten weeks he is able to follow a moving object and will turn his head away from bright light. He also probably smiles in response to cooing and the parents' smile. At twelve weeks he recognizes his bottle and other similarly familiar objects. Movement of the eyes are usually coordinated by this time. By five or six months there is increasing recognition of familiar faces and objects and certainly by this time, if not considerably sooner at two to three months, any deviations from the normally developing visual acuity may be recognized.

Part II

Syndromes

Syndromes are symptom complexes where a variety of manifestations occur. These are diseases where the visual problem may be only one of several that the child has. The number of these syndromes is great and many are quite rare. However, a brief classification is of interest.

A. Metabolic disorders
   1. Disorders of sugar metabolism

These disorders in the inability to metabolize various kinds of sugars may effect not only the internal organs of the body but also the eyes and sometimes the brain. Cataracts are one of its most prominent manifestations.

   2. Disorders of fat metabolism

Inability to bring fat through the various different channels of chemical reactions that normally occur sometimes results in various serious disorders in which the brain as well as the retina of the eye may be involved.

3. Disorders of proteins and amino acids

Amino acids are the building blocks of the proteins and disturbances in their orderly metabolism may produce far reaching changes in the eyes as well as the rest of the organs of the body. Some of these result in damage to the lens, retina or the nervous system concerned with vision.

B. Prenatal infections

These are infections of the unborn baby which disturb the function of several organs including the eye. Some of these infections result from invasions of viruses such as the German Measles virus, An invasion of the newly developing baby by way of the mother during the first eight weeks of the pregnancy may result in one or several disturbances, the major ones involving the brain, the eye and the heart. Last year an epidemic of German Measles (the medical name is Rubella) occurred in the United States and unfortunately a large number of these children have been born. The form of disturbance in the eye is usually that of a cataract. Another form of infection is that of a parasite. The most common specific agent is called Toxoplasma gondi - a disease which is called toxoplasmosis. This is becoming the most common cause of blindness among children at birth.

C. Systemic disturbances occurring after birth.

1. Generalized inflammations such as rheumatoid arthritis may affect children and if severe can involve the inner-coats of the eye sometimes leaving a serious disturbance in visual function in its wake.

2. Endocrine disturbances.

Diabetes in young children after some time may cause disturbances in the retina or in the lens of the eye. Proper medical care is very important. Thyroid function may be increased to such extreme degree that the eyes also may be affected.

3. Blood disorders

In severe longstanding anemia changes may occur in the retina and small blood vessels.

The above is merely an indication of some of the medical aspects of eye disorders in children.

Part III

Neurological and Psychological Considerations

The total integration of vision in the development of the psychological organization of the child is no where more apparent than when it is absent. No other sense can take over or substitute for the loss of vision. In a developing small infant all the senses are so intimately integrated with vision that by themselves they serve poorly until quite some time is passed. The child who has been blind since birth misses many of the visual cues for the initiation and imitation of his daily activities. Those who see cannot supply these cues for him. Nevertheless, if normal "he can conform to an impressive extent because through his interest at growth processes he is able to bring both formed forming patterns of behavior into desirable channels." (Gesell).

However, what happens when normal potentialities are not present? Certainly some failures in development can be ascribed to blindness, but too much allowance should not be made. If other structures, as often happens, are affected, correction of vision may not produce the expected results. Enrollment in special schools for the blind will result in disappointment. It is essential, therefore, that from an early age in infancy the child be examined by someone knowledgeable in normal growth and development. Often excessive preoccupation with the visual defect precludes this. The late result is very discouraging and disappointing when after several operations in years the parents find out for the first time that their child has organic brain damage as well.

Summary

The pediatrician's role, therefore, is no different than it is with any of his patients. He is concerned with the welfare of the child as a whole, and his progressive and orderly development. He uses his knowledge not only to detect and identify the child with visual defects, but to make sure that this handicap is placed in a proper perspective.

THE IDENTIFICATION, DIAGNOSIS AND EVALUATION OF EYE DISEASES

by Dr. Phillip Shahan, Ophthalmologist
St. Louis, Missouri

The role of the ophthalmologist in this program it appears to me lies in the diagnosis of eye diseases. The identification of eye problems, as Dr. Bloomberg has told you, is generally done by the mother. Within three months of age, as he pointed out, if the child doesn't see at all, the mother is acutely aware that something is obviously wrong. So the mother is the first line of identifying a problem. The second line is the pediatrician to whom the mother turns at once and it is his job to find out if this is an eye problem or a neurological problem or a hereditary problem which does not need an ophthalmologist. Then the third line is the ophthalmologist and it is his job to make a diagnosis of what the problem is, hopefully advise the parents as to what the future is (and this is perhaps the most important role) and carry out any treatment of the condition which may be possible or desirable.

Later in life (in the pre-school years) it is the role of the ophthalmologist to attempt some training in terms of recognizing letters and symbols so that the proper subjective evaluation of the visual sense can be made. Finally, it is his role to remain as a continuing advisor through the school years after the pre-school years are over. So my job is to find out what's wrong, fix it if I can and help out through the later years.

I found that it's a good way to introduce this subject briefly through a simple diagram of the structure of the eye. I believe that most of you have such a diagram in your hands. These diagrams are available from the American Optometric Association here in St. Louis in any quantity. I'd like to start with a brief analogy between a simple

Brownie camera and the eye, as a way of explaining to you how the eye is put together and what can go wrong with it. In a diagram of a Brownie camera, we have a box lined with black, a lens to focus the image and a plate of film in the back of the box. You're all familiar with that. This is all the eye is except for the fact that the eye is attached to the brain and the "film" is just the beginning of vision and not the end of the picture. Now to go on to the diagram of the eye, first the box. About four-fifths of the box of the camera is the white of the eye labeled on your diagram as the "sclera." In the front one-sixth of the box is a clear tissue called the "cornea." The sclera and cornea together are a single tough tissue about one-twenty-fifth of an inch thick and very tough, like a tendon, so when it is cut through it takes many weeks to heal properly. The cornea has the function of doing most of the focusing of light rays. Inside the cornea and sclera is the second layer of the camera which in that case was the black pigment. It is made up of three parts on your diagram, the first part is labeled "iris", whose function is to form a pupil and allow the light rays to come through. The second part is labeled the "ciliary body", the function of which is to hold the lens in place, to focus the lens for different distances of viewing and to secrete the fluid that maintains the intraocular pressure. The third part is labeled the "choroid," occupying the back five-sixths of the eye, the function of which is to stop the scatter of light rays (and that's the function analogous to the camera's black paint), and to furnish blood supply to the eye. These three tissues (iris, ciliary body and choroid) contain almost all of the blood vessels in the eye and are responsible for keeping the eye alive and making it a living organ instead of a camera. Analogous to the third part of the camera (the film) is the innermost layer on your diagram called the "retina." This is the place where the image is formed by the cornea and lens and this is where sight originates. So we have then three parts to the wall of the eye, the cornea-sclera, the iris-ciliary body - choroid, and inside that, the retina. One is for structure, the second is for nutrition, the third is for vision.

In addition to this simple box, there is suspended in the front of the eye, right behind the iris and pupil, the lens of the eye, which of course is normally transparent. It is suspended from the ciliary body by many little fibers. The retina is attached to the brain through a structure called the optic nerve which runs back through the rear of the eye and carries vision on to the brain. This whole structure is kept in a semi-rigid, tense state (in order to function adequately as an optical instrument) by the secretion of fluid into the eye from the ciliary body and the draining of fluids out of the eye in the angle between iris and cornea through the little hole there that is labeled the "canal of schlemm." This mechanism for maintaining a pressure in the eye is what goes wrong in the disease "glaucoma," where the pressure builds up because of some inadequacy in the drainage mechanism. An eye, in order to function, has to have pressure in it just like a tire has to have pressure in order to function as a tire.

This isn't all there is to the eye; the analogy of the camera is fine, but in addition to that, the eye is connected to what electricians or others might call a computer. The eye is sending signals back all the time and feeding information into the brain, and in between the eye and the brain there is a way-station much like a telephone switchboard. Anything that goes wrong above that switchboard, that is, back in the head, doesn't show up in the eye at all as something wrong visibly to the eye doctor or the parent. The cases where something is wrong in the brain, and where perfectly normal eyes don't see anything at all or sometimes see very little, are difficult cases for the ophthalmologist to diagnose, requiring the help of neurologists, psychologists and others.

Now a word as to what can go wrong with the eye itself in terms of diseases by name, and a word about how to recognize these. First of all, the cornea is normally crystal clear and transparent so that when you look at a person and see the color of the eye and the black pupil, you're looking through a transparent cornea, like the crystal on a watch. And if there's any haziness between you and the pupil and iris, something is wrong with the cornea. This is how glaucoma usually shows itself in infants and children, just a grey haziness of the cornea along with a little redness of the white of the eye. In addition to that, of course, there are obvious infections of the cornea and other things that can go wrong. Perhaps the most common thing that we see in infants, that we can do something about, however, is cataract; and for those of you who don't know what cataract is, it is an opacity or haziness of the lens inside the eye. With cataract, the lens, instead of being crystal clear, is more or less opaque and it is diagnosed or noticed by the mother because the pupil appears white instead of black. The normal pupil, as you know when you look at an eye, is perfectly black, as it's just a hole in a dark box. When it turns white, however, it means that the lens behind has become opaque and that's how most such cases are found by the mother. Virtually all cataracts of infants are due, as Dr. Bloomberg said, to German Measles in the mother. Glaucoma and cataracts are two of the diseases, then, which can be noticed by the mother, pediatrician and ophthalmologist, and about which everything can be done, to preserve sight in the case of glaucoma and to restore sight in the case of cataracts. Unhappily, nearly everything else that causes blindness we can't do much about. The hereditary atrophies of the optic nerve, the hereditary absence of the brain, the hereditary absence or malformation of the eye to a severe degree, the inflammations of a severe nature that occur in the retina and choroid, don't show on the front. Nobody notices them until it is apparent later on that the child doesn't see. I think it would be unwise to run through the gamut of diseases here because we're going to meet with the parents and the children later and discuss each one separately with the parents.

Now a word as to the examination of a child, how to prepare the child to be examined, more or less, about which I understand our educators here are interested in order to pass this information on to the mothers.

First of all, in infancy: there is no advice you need to give the parents. Just bring the baby in and then it's a matter of force; who is stronger, the child or the doctor. With a child under one year of age, there is nothing to do except force the child to be examined. Between one and three years of age, after the brain has developed to the extent that it is going to, is a vital time in a blind child's life to receive stimuli from all his other senses. All too commonly the parents of a child who is obviously blind at age one will just leave him shut up in a dark room somewhere, thinking that he doesn't need to have any light or any company or anything. So the child, because he is blind and through parental ignorance, is not allowed to receive all the experiences that he might get through his senses of touch and taste and smell and hearing. That's the only way the child is going to learn anything, through these senses, and so parents of pre-school children, of course, should be strongly urged to get that child with people, to get him out in order that he might have all the experiences he can. This is where your greatest goal as pre-school advisers can be, in urging the parents to give the child experiences with everything, so that he can learn through his other senses, and without, of course, being so overprotected that the child is smothered.

Secondly, with regard to examining these children at age one to three, it is impossible to do a subjective examination and ask for them to respond to you as to what they see or don't see. But an objective examination can be done very well and these children should be prepared by the simplest of all things, getting up close to the child and shining a light at him so he won't be afraid when this happens. Everything the eye doctor uses for the diagnosis of the child, or anybody else, depends upon shining bright lights in the face, and the child should not be afraid when he first comes to the eye doctor. Third, in the preschool years of ages 3 to 5, it is important to prepare the child for a subjective examination during which the child actually tells the doctor what he sees or doesn't see. There are many aids available for that, one of the simplest, this little E block, is made for a couple of dollars by instrument companies, but is supplied free by Smith, Miller and Patch Pharmaceuticals.

This can be played with by the child (if he has enough vision to see), and the E can be turned in any direction. You're all familiar with this E test, the child shows which way it goes or else he has one in his hand and points it in that direction. So those two things are important, the bright light and looking at something like the E block.

Other means of testing vision are pictures, and the Schering Corporation will furnish this picture chart to anybody who wants it. It's a picture chart with an E chart on the other side. The Mosby Publishing Company (St. Louis) will be glad to sell you this second type of picture chart which is the one I use in my office. My great uncle, Dr. Ewing, who was a St. Louis Ophthalmologist, devised these pictures of a certain size to go along with the Snellen chart back in 1888, so these are my family pictures.

An interesting by-play on these pictures: when I first went into practice 18 years ago, there was a horseshoe in the series and that was the one that most children did not recognize. Since television has become popular though, the horseshoe is easy for them, but they don't recognize the cross. So, that's what television has done.

IDENTIFICATION, DIAGNOSIS AND EVALUATION

BY Robert McQuie, School Counselor
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My concern is with the young blind child as he makes his first appearance here at school and with what the parents can do in order to prepare the child for my work with him.

Perhaps when you bring your child to school the summer before he starts to school here, possibly early in the school year, maybe toward the end of his first year here, but hopefully by the end of his first year here, I will have had a contact with him in terms of psychological examination and this is the matter about which I would like to talk with you. You are probably quite familiar with the IQ and psychological examinations, as we haar a lot about them nowadays. You probably know that the average person presumably has an IQ of about 100, that the average college student has an IQ somewhere in the neighborhood of 120 and that the person who has an IQ of around 80 probably isn't going to be able to complete a normal high school program. If all of our psychological tests were perfect instruments, and if every person grew "normally," then a person would have, throughout his lifetime from the cradle to the grave, the same IQ. But, of course, our instruments are not perfect and very few individuals grow normally, so there are some variations. Sometimes the variations are quite great and we probably find greater variations in our situation here than is found in any other educational situation, because we find that the visually handicapped child has missed out on a lot of experiences during his pre-school years, a lot of experiences that the sighted child would have. So far we don't have an instrument that really takes this into account. So when I give this first IQ test, I expect that the very large majority of the children will attain an IQ of something in the 60's or 70's or 80's. Very few five and six year olds we have coming to the school are going to score 100 or better on our present IQ tests. This doesn't disturb us a great deal because we know it is going to change as the child gains in experience and progresses along in the school program.

But,of course, we don't really find out what his ability is or what his possibilities are, we just find out a little bit about the situation under which he is currently operating. This is helpful to us because it helps us to find out the things that he needs to know more about, the things on which we need to work with him to help him to better prepare himself for his educational program. We try to de-emphasize this matter of just what the IQ score is, particularly when we're talking with you parents or when we're considering the scores among ourselves. So, the IQ score itself really doesn't mean very much at this stage of the game.

I might point out to you that since the child is behind in a number of these experiences, we are very likely going to retain him in the first grade and maybe again in the third or fourth grade, and we like for you to be prepared for this. Unless he is a very, very unusual blind child who has had a lot of experiences, he's not going to graduate from high school when he's 17 or 18 years old; he's going to graduate from high school when he's 19 or 20 or 21 and we hope that you will begin to prepare your thinking in those terms. This doesn't mean that he's not intelligent or that he is mentally retarded or anything of this sort, it simply means that he's moving more slowly, as he might be expected to do, and that we can help him pick up the things that he has lost if we retain him in the first grade and perhaps again in the third or fourth. In order to work on this at the Missouri School, we have set up a second Kindergarten, another room that many of our children go into before they go into the first grade, so that they are actually in Kindergarten, in a readiness program, for two years instead of just one.

I'd like to tell you just a little about some of the things that are on the IQ test that I'm going to be giving your child if he happens to be coming here to school. I'm not going to say too much about it because I don't want to tell you exactly what's going to be on the test, but I think it's important that you know some of the things we do consider important in this matter of preparation. You probably have the idea that because your child can repeat all of the commercials that he hears on television and can sing all the songs that he hears, and knows all the words to them, that this means that he is intelligent. Well, it doesn't mean that, it simply means that he might have a reasonable amount of intelligence. We can be reasonably certain that if he can't do these things, there is something wrong with him. But just because he can doesn't mean that he has any great degree of intelligence, because this is only one very small item. And as far as repetition goes, it's really more important, rather than for him to repeat his ABC's or count from one to twenty without making a mistake or repeat all of these songs and commercials and so forth, that he be able to repeat after you three letters in a row, or a sentence of five words, or four numbers in a row that you give to him right on the spot, with him repeating them back to you right at once. This is much more an indication of some intelligence rather than the fact that he has heard things over and over again and can repeat them. So I would urge you to start even with the very small child when he first begins to talk and say some numbers and some words and some phrases and ask him to repeat them back. This is what he's going to have to do in the classroom and the teacher sometimes gets pretty perturbed when the children can't do it. This is one thing to which you can give some attention.

The small child should be learning something about sizes and shapes and lengths and so on. Parents can help by taking two objects and asking him which one is bigger, or which one is heavier, or which one is longer, or shorter, or lighter, and so on. These are concepts that he should have. He should certainly have the concept of pointing to the different parts of the body when you ask him to, and of identifying common objects by touch, if he can't see. These are things that you should be working with him on just as soon as he begins to get around and get into things and to talk about things.

Of course we're interested in his ability to define things or explain what something is: what is a chair, what is a table, what is a bird, what is something else. We're also concerned with what some of these things are made of: what is a table made of, what is a house made of, etc. The tests that we're using right now, which I'm happy to say are being revised, cover these things from the age of 3 up till about the age of 7, so naturally I don't expect the pre-school child to be doing all of these things that I'm talking about. However, these are things to which you could be giving some attention.

Your child should also be noticing some similarities and differences: what is the difference between a table and a chair, how are a table and a chair alike.

My own children are now ages 7 and 5 and the younger daughter was pretty slow in starting to talk, but as soon as she was a little past two and really got started talking, we began with her and the older one, who of course at that time was almost 5, to play games on telling how things are alike and how things are different. Of course we would give the harder questions to the older girl and the easier ones to the younger, but as long as each got her turn, it was fun for them and they didn't mind doing it. The older one didn't get upset if she had a harder one as long as she could answer a good many of them, and she enjoyed doing it. I'm led to believe that the blind child would enjoy doing this too if we took some time out to try some things like this. We also spent quite a bit of time working on rhymes: what is a color that rhymes with true, what's an animal that rhymes with box, things of this sort. The children enjoyed doing it, particularly when we were going on a trip, going up to visit Grandmother who lives 80 miles away. This would be how we would spend our time in the car, going over some things such as this. And they enjoyed it as long as we didn't wear them out. They still want to do some of it, and so now they're wearing me out with it.

Through these games, of course, they began to become interested in why certain things are the way they are, and really this is eventually going to be the crux of much of a child's educational situation, the ability to explain why certain everyday things happen the way they do, why certain situations are the way they are. These types of tests don't usually appear on an IQ test until after a child starts to school but he should be getting some preparation for them and be interested in them and you should be interested in answering the "why" questions that you will get, as far as you feel that you can and should answer them. Things like names, dates, whether he's a boy or girl, whether its morning or afternoon, the month and the year, the days of the week, these are things that are important for them to know, but not just to answer a question or just to be saying them, but rather to give answers with some understanding. If he's going to name the days of the week, he not only needs to know the days of the week, but he needs to know that Monday comes before Tuesday and Saturday comes after Friday. It's not enough just rattling through the names of the days of the week, but it's important that he have some understanding of these things. This again is on a little bit higher level.

In his number concepts, I made reference earlier to the matter of counting. It's fine if he can count from one to twenty but as I said before this is not really a measure of intelligence. The measure of intelligence is whether or not he can take those three pennies that you're giving him and count the three pennies correctly. When I started to school, there was great emphasis, and perhaps still is, on children not counting on their fingers. As far as I'm concerned on an IQ test situation, I would much rather have a child count his fingers, as long as he's counting something, than to have him just saying a bunch of numbers. So it's important that, in this matter of counting, he actually be counting objects, picking things up from the table and putting them into his hand or taking them from his hand and putting them onto the table or counting them into a group and pushing them over to you, and not just saying a group of numbers.

Also in the IQ testing, there is the matter of repeating things backwards as well as forwards, and you might even want to start with this in terms of two numbers, or two letters, or two words, or two something. See if you can get over to him the idea of what is the differenc between saying something backward and saying it forward, or saying things in a particular order. And then, of course, there is the matter of getting him acquainted with coins, pieces of money, the values of them and the simple addition and maybe even subtraction, when we talk about going on beyond the pre-school years.

All of these are things that are included in the IQ test that your child will have as a small child and as I told Mrs. Murray last evening, I don't think that you can really prepare him for the test in the sense that you can make the test easier for him, but by giving some time and effort to these things, you can certainly give him some experiences that will help him meet what's on this test and, in turn, meet the demands that his classroom teacher is going to set before him. I would be perfectly happy if the child who is going to score 120 on the IQ test as a senior in high school would also score 120 on the IQ test when he's in Kindergarten. Therefore, if my mentioning these things to you would help him do that, then I would be perfectly happy to have it happen that way; he's not going to score anything better than he is really capable of doing. We may have difficulty taking some of the abilities he has and helping develop them. This will add a little bit to our burden of work, but that's all right -- we would like to have that challenge. I would urge you parents to go into these things with your pre-school child, as many of these items as you possibly can. Don't be concerned if he doesn't catch on to all of them and certainly not as rapidly as you'd like him to, but he may enjoy a lot of these things that you never thought of trying with him.

These are all verbal type items. More and more of the testing nowadays is going into the performance skills,a matter of stringing beads and things of this sort. We shall have to tell you more about that, at least I will, in terms of the psychological testing, later on when we have had some experience with that type of test. Mrs. Murray can certainly tell you about some of these things in her experiences of working with the pre-school child.

COUNSELLING WITH PARENTS OF BLIND CHILDREN
"A Social Worker's Point of View"

by

Miss Marie Morrison, A.C.S.W.
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Thank you for inviting me to discuss with you services to pre-school blind children. This invitation came to me at a time when our agency in Columbus was considering the possibility of a total children's service in the community. We are somewhat like the city at the foot of the mountain which can be entered by one road. The road has a sharp curve which many motorists do not succeed in getting around. The city then has two alternatives. One, it can provide ambulance service to pick up the drivers who didn't make the curve or, two, it can build a fence around the curve to prevent these drivers from falling. Truly, those of us in work with the blind must think in term of building the fence. This means we must get to these children early, at the time blindness is first discovered, if our work will be effective with their families.

In Columbus we are considering: (1) Diagnostic Services, including medical, psychological, neurological, social, and the many other services which may be involved in a diagnostic process. (2) Treatment to correct any of the conditions found in the diagnostic process. (3) Case counselling with the parents of young blind children from the time when blindness is discovered and in cooperation with the diagnostic team and treatment service. (4) A nursery school for blind children at which time they would be taught the usual nursery school work plus help in the special problems of blindness; namely, mobility, communication, and attitudes toward self and others. (5) Somewhere in this training we hope to have help for the children in the area of working out the blindisms which many of these children develop. They should then be more ready to enter school with seeing peers. Such a service must be arranged so that each child will be individuallyconsidered and certainly not all children need all of the services listed above. Such service can be accomplished only through the cooperation of many professional disciplines. There is no one person or even one area of service that has all the answers. In this day of specialization, we find professional persons are specialized within their own field of practice. For example, doctors for the most part are no longer general practitioners who provide the total medical care for the family. Certainly the doctor is not the family counselor as he was in the days of the family doctor. Today doctors specialize within their own fields so that they are opthalmologists, orthodontists, pediatricians, etc. Teachers specialize not only in subject matter such as English, History, etc. but in special education, secondary, elementary and so forth. Social workers also specialize in case work, group work, and community organization. Today I want to confine my remarks to the case worker's point of view. In preparation for this talk, I read all the literature that I could find pertaining to the subject. I found that there was very little literature on counselling with parents of blind children. There was a great deal of literature on blind children of school age pointing out the many problems encountered by these children, the main problems being attitudes of these youngsters, ability to relate to other young people with self-confidence and social poise, lack of mobility, communication, social skills, etc. In Columbus we have 237 blind children who have come to the Agency for services. I looked at those cases with which I had worked and found some social or emotional problem which prevented each child from reaching his maximum adjustment in school, whether the local community school or the state residential school.

One mother who came to me applying for a campership for her young blind child told me that she had no problems with her child. She reported that everything was fine. Her child was well adjusted. The other children in the family and in the community accepted him. Within a very few minutes she said to me with tears in her eyes, "You know I drove up to the local grocery store and my child said, 'Oh Mother, look at those water melons.' How was I to tell him that those were not water melons but bags of peat moss?" All the parents with whom we had contact asked in some way for help in coping with the situation which the blind child presented. If I may be personal, I can remember an incident when I was a child when my mother asked me and my sister to wash the dishes as a share of our responsibilities in the household. A new neighbor moved in across the street and, upon observing me and my sister washing dishes, said, "You know if I had a child like that, I would never make her work as you do this child." After the woman left, I proceeded to tell my mother that I would rather have that woman for a mother so I wouldn't have to work. My mother then proceeded with the paddle; however, I think this was difficult for her as it is with most any mother or father of a blind child.

I would like for us to consider social case work. What is it? What does a case worker do that is different from other professions? When should a client be referred to the social worker? And what should be the relationship between the social worker and other professions?

Defining social work is difficult. Many authorities have written pages. I shall try to shorten that by saying social case work is a process of social study, diagnosis, and treatment whereby the case worker enables the client to work through certain feelings which block his handling of life's situations. The case worker must listen to, understand and discuss his situation with other professional disciplines working with this person. The worker must understand the client's problem and why he is having the problem. The problem which the client brings to the social worker frequently is not the underlying one at all. Recently a mother of a pre-school blind child requested help from our agency in learning of educational facilities available for blind children, although her child was just an infant. When the social worker called, she learned that the mother knew as well as the social worker did of the existing educational facilities. Her real reason for asking for help was her concern for having a blind child. She left this infant in his bedroom constantly and was ashamed to present him to any of her friends because of his eyes. Quite often blind persons come to our agency for help requesting that they learn braille. As we examine this with them, frequently they say, "My doctor told me to come here and learn braille." Braille is actually the fartherest thing from their minds and to begin instruction in braille would possibly cause the individual who is extremely fearful of losing his sight to become seriously ill mentally.

Social case work methods differ from psychiatric methods in that the social worker deals with the rational person. She strives to give ego supportive help. This means, of course, that the social worker does not pat the client on the back and say that everything will be all right. Neither does she give advice. Rather it is a slow process where the client talks about his feelings and is given insight into why he feels this way and how to cope with these feelings and his situation. The case study, diagnosis, and treatment is an ongoing process on the part of the social worker. This service then must be provided through an on-going relationship of respect between the worker and the client.

The case worker helps the parents of a blind child with their feelings about blindness so that they in turn may have more realistic expectatic for their child, thus permitting the child to develop in as normal a pattern as is possible.

As stated in the book, Social Case Work and Blindness, "What parents believe and feel about their blind children, what goals they have for them, and how they behave toward them has a great deal to do with the development of their children. In the case of a young child who is blind, the key to the world is held by the parents." Dr. Margaret Ribble in her book, The Rights of Infants, wrote "The attitudes which parents hold during a child's first year of life are reflected in the child's feelings. Definite evidence of extreme feelings of parents can later be observed in the child's nature."

The White House Conferences on children have constantly reiterated the need for every child to have a home, love, understanding, and the development of his personality as his most precious rights. These must be the rights of blind children as well as seeing children; however, as a parent recently said to me, "We parents are normal human beings. Just because we happened to have a blind child doesn't mean we are suddenly gifted with super intelligence to know how to handle all the situations which we encounter."

It would certainly not be normal for parents to welcome having a blind child or to point out that they would feel good about it; therefore, they do need help in working through their feelings and in understanding how to cope with the situation. The parents should be referred as soon as they have been informed about the blindness of their child.

Fragmented services, I think, can do more harm than good; therefore, the social case worker must work closely with all other persons involved in the case situation. If the child is of school age or nursery school age and a teacher is involved, the social worker should be in touch with the teacher. The social worker should contact persons from the medical profession who are involved in order that she can understand the medical problem and in order that the doctors involved can better understand the home situation. Also, these workers need to understand what each is doing in regard to planning with the child and the family. Again, we are all human beings, sometimes we misunderstand. Workers may find themselves being played against each other. I remember one time when I visited a county welfare office I found the worker quite upset with me. She said that the client had told her that I said she should give the client more money on his Aid to the Blind check. I said to the worker that I had wanted to talk with her because the same client had told me that she said that I should provide certain equipment that was available to all blind persons. She immediately said, "You know, I didn't say that." We then decided that the client had believed what he wanted to believe and was using it to his own advantage.

Clients may be hurt by the lack of case conferences and cooperative planning. This was clearly observed in the case of Judy, age 14, who was referred by the school because of behavior problems. We found serious problems within the family. Judy was blind from birth. The family was financially independent and felt that seekin help for this child would be a sign of weakness. Judy's mother rejected her, then felt guilty because of her rejection. Judy's father worked long hours, six or seven days a week. Her mother stood by the window watching Judy play in the street "fearful that a car would hit her." Case planning involved psychiatric treatment for the mother, supportive counseling for the father, and enrolling Judy in a special residential treatment center. However, a social worker, who was not trained in social work beyond a Bachelor's Degre entered the case and decided to get a summertime job for Judy and talk with the mother each week about blind teenagers. She did not conference the case but moved ahead with her planning. After her visit to the home, Judy's mother, who felt at first that she should go along with the plan, was faced then with the reality of having the child stay with her, so had a psychotic break and had to be hospitalized.

Coordination of services and cooperation among workers are essential. Case planning must be centered on the individual and his needs. Workers must be very careful to help persons, whether we call them students, clients, or patients, to become independent. In our Agency we do not speak of a case as "my case" but as a human bein whom we are trying to help. We must consider above all the individua his needs, and who can best meet these needs. If we keep our goals centered on the individual who comes to us for help, we should have no problems in cooperating with each other and in planning for the client's best interest.

An illustration of goal cooperation was a case that a teacher referred to me concerning a six year old blind child, Jane, who was totally helpless at school. She could not unbutton her coat, remove her boots, or even feed herself. The teacher felt there must have been some problem with the family. The child seemed withdrawn and was unable to participate in any of the classroom work. I called on the home and found that both parents worked. There was a 23 year old girl, Sue, in the home who was unmarried and unemployed. She was crying when I arrived because she had just placed Jane in a taxi-cab to go to school. She said she hated so much to see her little sister leave every morning, that since the child's birth she had taken care of her, in fact, had done everything for her. She had even let her little sister sleep with the lights on because the littl girl was afraid in the dark. (This child was totally blind and was incapable of distinguishing between light and dark). She had, as she put it, spent her life for her little sister who was now "being taken away from me." We began to work with Sue, helping her better understand her feelings and how this was affecting Jane. We later helped her become involved in volunteer activities. Gradually, with help, she was able to permit Jane to go to school without weeping. She was also able to teach Jane some skills of daily living, such as feeding herself, etc. Constant communication between the teacher and the worker helped both to understand what the other was doing as the teacher worked with the child in school to continue to help her learn to be more independent and the social worker worked with the sister and the parents as the parents were helped to understand the needs of both daughters. They, too, were able with supportive help to correct this situation.

In summary, we can say that parents of blind children are human beings who are not suddenly gifted with special knowledge to handle the problems presented by the blindness of their child. The social case worker can be helpful to the parents in working through their feelings about blindness so they can help their child develop as normally as is possible, just as they do their other children who are not blind. The parents are the key to the child's future and they must have help if the child is to develop normally. Case counseling should begin as soon as the parents know the child is blind. A coordinated service is needed in order to meet the needs of the total child. Case counseling is a most vital part of this coordinated service.

SOME THOUGHTS ON THE EMOTIONAL DEVELOPMENT OF PRE-SCHOOL CHILDREN

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We have a body of knowledge about personality development which I would like to share with you. I don't have much first-hand knowledge of how blind children develop although I have seen a few children who were partially or totally blind.

What I would like to do is focus on certain tasks that all children must master, and comment on some special difficulties a blind child might have in achieving each task. I don't mean to imply that all or even most blind children need to be seen by a child psychiatrist but certainly the loss of vision brings about a special way of developing.

In general, I conceive of personality development proceeding in a series of stages. Each new stage is ushered in by new capacities and is qualitatively different than the preceding one. From birth to six months of age is one stage. The infant is getting his basic equipment in order. About six months of age, normally a person can recogni that the infant has a unique personality of its own, and the second stage goes from about six months to about fifteen months. The third stage, the toddler stage, when the child begins to walk, goes from fifteen months to three years of age. This stage involves walking, talking, becoming independent, and so on. A fourth stage from three years to six years of age is the questioning stage. The child asks, "why, why." He asks questions about death, sex, illness, etc., that are very difficult to answer. A fifth stage from seven years to nine or ten years of age is marked by great industry and learning as well as a turning away from the home to school and his peers.

Let's go back to the first stage, from birth to six months of age.

What usually takes place then? The first three months are a sort of "shake down," the infant is getting his instinctual apparatus in order so that sucking goes smoothly, his various bodily systems settle down, etc. Ordinarily a sighted child responds to seeing his mother by smiling at around three to four months of age and he babbles and coos.

Here is the first hurdle a blind child must make in reference to his emotional development. It isn't that many blind children do not learn to be responsive, but they don't have the visual cues. The mother-child interaction is a mutually reinforcing one throughout. For instance, in an older child, as the mother reaches for him, he lifts his arms to be picked up, and in an infant of around five months of age, as he sees the bottle being warmed, he can more or less successfully put up with the delay before he gets it. There is less of this mutual reinforcement if the child cannot see, and the mother must work harder with less feedback.

In this first stage, there is a second handicap I would like to mention. We all tend to freeze when we are listening and concentrat When the blind child hears his mother approach the crib, he tends to listen and so he freezes rather than reach out toward her. Superficially this may look to the mother as if he is unresponsive. As one mother put it, "He doesn't seem to need me." Yet the blind child needs more stimulation than the sighted child.

Also, if the parents haven't already discovered that their child is blind, usually they notice it sometime during this first stage. In the initial shock of the realization, they naturally react with hurt, guilt and depression, which interferes with the spontaneity of caring for the child.

In the second stage, from six months to fifteen months, many new things occur. Normally, creeping and crawling take place. The child normally develops eye-hand coordination, reaches out for toys, brings them to him to explore, etc. Ordinarily the child begins obviously to recognize mother and, to a lesser extent, the rest of the family, and to have what may be called, "stranger anxiety," which is to say that he will cry when a stranger too quickly tries to be friendly.

In this second stage, a blind child again has handicaps. While blind children usually sit well and obviously are ready to creep at five to seven months, all too often they either don't creep or have an unusual kind of locomotion that has been called "pin-wheel locomotion," which is a kind of pivoting or going in a circle. Also, a blind child often seems to be content to lie passively on the floor for long periods of time. At this time, if the parents are concerned about retardation, they may mistakenly assume that the child is retarded. Another handicap with which the blind child is confronted at this stage is the whole idea or concept of the permanence of objects. A sighted child in late infancy will seek objects that fall, he will love games such as hide and seek, etc. But a blind child makes fewer or no attempts at this time to recover an object. It is as if he finds it hard to realize the toy exists out there away from personal contact. Another handicap that is the result of lack of vision is a replacement of eye-hand exploration. With many blind children, mouthing of objects continues to be an important way of knowing and learning, long after sighted children have given this up. Smelling and tasting is involved here too. This is unfortunate in one respect. That is, it delays the child's use of the hand itself as a tool in personality development at an age when it is most appropriate. Later, of course, the hand becomes very importar to the blind child, but often the blind child can't depend on the hand alone until he is two years old.

The third stage, from fifteen months to three years of age, the toddler stage, ordinarily involves walking, talking and taking the first steps to become independent. Normally the task here of achieving a good sound independence which is age-appropriate is a stormy period as evidenced by the common phrase, "the terrible twos." But this separation from mother with the beginning of self-reliant functioning are very important for the future self-confidence and identity of the child.

This phase of dependency-independency conflict usually lasts considerably longer in the blind child, often until he is five or six years of age. One factor involved concerns the child's capacity to orient himself to his surroundings. Normally a child learns to orient himself to increasingly larger spaces, from the lap to the playpen, to the house and yard, to the neighborhood and so on. With the blind child, this orientation to his surroundings is slower and takes longer to acquire.

At four to five years of age, with the blind child even in familiar rooms, the precise location of the door may be momentarily forgotten. Also, when the blind child is tired or too upset, he tends to get lost easier for it requires extra concentration to keep things in place.

Yet, while the blind child needs to learn how to be independent, his particular needs require prolonged dependence as well. There are many activities a blind child at this age cannot learn to do, since they are either too dangerous (such as playing near a busy street) or impossible (as picking up many small objects that happen to be spilled). The blind child sooner or later realizes that other people can be successful where he himself fails.

Often the blind child will say, "I want to do it myself," yet holds on to the adult. It is as if he is saying, "Let me be the active on but don't hold me, I'll hold you."

Unfortunately, blind children are picked up and dumped as if they were inanimate. Their fear of being abandoned tends to lead to compliance since they know from experience that they can't cope with strange environments if deserted. This compliance may look as if they are good children but, if too frequent a pattern, it interferes with their learning to be independent.

In this toddler stage, the child is learning how to handle his anger and aggression. Ordinarily, the sighted child's vigorous physical activity helps greatly in this learning. Also, the sighted child can not only see the consequences of his anger or aggression but is better able to be forewarned of others' anger. (They can see an angry face or see a threatening gesture.)

The blind child's restriction of muscular expression gives him less opportunity to try out different ways of handling aggression. He also can't know as readily what happens as a result of his acts and so he must fall back on his imagination. His imagination, unless he can verbally keep it in line, usually exaggerates the consequences so that the blind child tends to be overcautious. Another related handicap is that the blind child is less able to anticipate aggression directed at him and so he tends to have a greater fear of being attacked. Yet he has less freedom of movement either to fight back or to run.

Just a word about language and then I'll have to stop. Ordinarily, after babbling and the first words have appeared at ten to fourteen months of age, the sighted child rapidly increases his vocabulary of words from fifteen months to three years of age. Many blind children have a temporary delay here. This may be because their wishes necessarily are more often anticipated, but also, without vision there is less stimulus to name objects. With sighted childr an adult normally looks at the named object or the child can see the object. It is not easy to continually remember to have the object felt or touched or smelled by the blind child.

But as the blind child begins to use words, parents usually are delighted and the blind child by four years of age often has a relativ large vocabulary. But what sometimes happens is that imitation or parroting of the words plays too large a role. That is to say, both since the mother gets so much pleasure out of receiving a response but also because the child enjoys pleasing the mother, the notion of the child really learning to know and associate all of what is contained in some named objects tends to get overlooked.

I hope I haven't given the impression that I consider all blind children as being deviant in personality development. I know this isn't so. But the road of healthy personality development is strewn with more obstacles for the blind child, and his parents have that much more difficult of a task in doing what is necessary to provide healthy opportunities for their child.

CHILDREN'S BUREAU HEALTH SERVICES FOR CHILDREN WITH VISUAL HANDICAPS

by Alice D. Chenoweth, M.D.
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The spokesman for children in your Federal government is the Children's Bureau, which is one of several agencies of the Department of Health, Education, and Welfare. It was created in 1912 to "investigate and report upon all matters pertaining to the welfare of children and child life among all classes of our people." In carrying out this broad mandate, the Children's Bureau has had not only a concern for all children but, more often than not, it has been the champion of disadvantaged children, which, in the context of this conference means children who are blind or visually handicapped.

Since 1935, with the passage of the Social Security Act, the Children's Bureau has had the additional responsibility of administering three grant-in-aid programs, two in the health field, and one in child welfare. The two Federally-supported health programs are called maternal and child health and crippled children's programs. Each State and Territory and the District of Columbia has an MCH and CC program.

Because we are here to share our common interests and concerns and plan more cooperative activities in the future, may I suggest that an important first step is for each of you, as members of the American Association of Instructors of the Blind and as representatives of other agencies, to seek out the staff of maternal and child health, crippled children and child welfare services in your States and find out what their program consists of. All divisions of maternal and child health and the majority of crippled children's agencies are found in State departments of health; all child welfare programs are in State departments of welfare.

Maternal and Child Health Services

The possibilities for joint action are many. For example, two director of maternal and child health have recently told me they were cooperating with State agencies for the blind to co-sponsor a workshop for parents and children who are blind - workshops which are similar to the one being held concurrently here at the Missouri School for the Blind for parents and children. Each year, maternal and child health funds support a great many conferences and institutes on a variety of subjects.

For many years MCH funds have been used to purchase silver nitrate capsules or other prophylactic drugs to prevent ophthalmia neonatorum. When the cause of retrolental fibroplasia became known, MCH divisions developed a variety of preventive activities - such as the dissemination of information to professional groups and the purchase of oxygen analyzers to measure the percentage of oxygen to which the premature baby was exposed. Now, as a result of the 1964-65 German measles epidemic, the Children's Bureau and the State programs are again active. Some MCH funds have been used to purchase gamma globulin for mothers exposed to German measles.

Many MCH programs support services for prematurely-born or low-birth weight infants, who have among other defects a high incidence of visual defects and abnormalities of the eye.

Under the Maternal and Child Health and Mental Retardation Amendment of 1963, the Children's Bureau is able to make special project grants to provide necessary medical and hospital care to low-income women living in areas where they do not receive the prenatal and other maternity care services they need. Through maternity and infant care projects "comprehensive" services are available to "high-risk" mothers and "high risk" infants in the hope of preventing physical and mental defects and disability in infants.

At this conference, there has been frequent mention of the multi-handicapped child. In 1956, the Congress earmarked a million dollars of MCH funds for mentally retarded children. A major use of these funds by the State agencies has been the establishment of multi-discipline diagnostic, evaluation, treatment, and follow-up clinics. Many of these have in fact become clinics for the neurologically or multi-handicapped child.

Usually, the physician in charge of the clinic is a pediatrician, often with some training in neurology. Other medical specialists, including the ophthalmologist and the psychiatrist are available for consultation. In addition to the nurse, medical social worker, clinical psychologist, who are usually needed full time, the services of disciplines such as audiologists, nutritionists, dentists, speech, occupational and physical therapists may also be available.

Children's Bureau funds now support in whole or in part 94 such clinics; a directory listing "Clinical Programs for Mentally Retarded Children" is available from the Children's Bureau.

For many years, maternal and child health services have included vision testing as a part of conservation of vision and of school health programs. School-age children have been the chief beneficiarie in most of the States. However, vision screening of pre-school children is increasing. A new publication of the Children's Bureau is "Vision Screening of the Pre-school Child."

Crippled Children's Services

The second grant-in-aid health program administered by the Children's Bureau is the crippled children's program. In the words of the Social Security Act of 1935, the Congress provides crippled children's funds "for the purpose of enabling each State to extend and improve... services for locating crippled children, and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling...

As the name implies, State crippled children's services started chiefly as programs for orthopedically handicapped children; each year the conditions for which States provide services become more inclusive. For example, New York State announced within the past year that a child with any type of disability or handicap or chronic disease is eligible under its program. Children under 21 are eligible for services.

In 1962, 12,400 children with strabismus, 775 children with congenital cataract, a total of more than 23,400 children with some kind of eye condition, received services under official CC programs. Among the children given service were children with retinoblastoma, children who needed corneal transplants, and children with amblyopia ex anopsia. Between 1950 and 1962, the number of children with eye problems cared for by CC agencies has increased by more than 340%.

REFERRAL TO AND USE OF COMMUNITY RESOURCES

by Roy A. Davidson, Executive Director
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My presentation is on a subject that is broadly known as community resources. When you start talking about community resources for childrer with vision problems and problems of other handicaps, you run into quite a gamut of things to consider. You can't consider community resources as being anything that does not begin and end with the family. Community resources, by and large, are therefore resources of the family; resources of the local community which would be the town or the locality the person lives in; next, the resources of the area which is generally described as the state; and last but not least, resources that are applied nationally. Most of the national resources that are available come to us in very filtered quantities and sometimes very filtered quality, although at other times they can come to us in concrete fashion. Usually the application of services and the obtaining of community resources is based on more intimate levels than that of national application.

In studying community resources and to be cognizant of them, a person must have a knowledge of the problems of visual impairment and blindness. He will be acquainted with the cause and frequency of blindness, the specific special education methods and needs necessary to affect a youngster's habilitation or rehabilitation, depending upon his visual disability.

We must have a thorough knowledge of what actually the child needs in order for us to be able to describe the, let's say, "accident of community resources," because I think in many ways community resources are a matter of accident. This matter of accident is your own interpretation of what they are. You may have heard the statement, "there is no such thing as 'words mean', it is 'people mean'". This is true with community resources. There is no such thing as "community resources," it's resources that people "mean," or that people conceive, so "resources" are a figment of imagination just as the definition of a word is a figment of your own thoughts. It's your own idea of what you mean, as a person, rather than what the word itself describes, since the word itself describes something different to each one of us related to our background and our training.

How to obtain community resources and services, and how to decide whether they are applicable or not, is really the valid and the great skill of the resource finder. The resource finder can be, in many cases, the teacher, the administrator, the social worker, the nurse, the parent or just anyone who is looking for something to help the visually handicapped youngster. We have to know that in order to make community resources effective, there should be a plan devised to assist the youngster with his treatment, his training, and his education. There is a necessity for developing a long range plan for each youngster. I think community resources generally are shortsighted in the fact that they think only of solving an immediate problem. It's like education itself. Education sometimes gets away from the total education or development of the child because it becomes an end within itself. We have to stop to think what the purpose of a geography lesson is, or what the purpose of learning braille is, or what the individual purpose of a single rehabilitation or community service is.

The plan of using community resources should never terminate until the youngster has his maximum vocational growth as a handicapped individual. The maximum vocational growth may be an adequate fitting into home life, as a homemaker in case we have a girl we're concerned with, or it may be employment in terms of a job as far as the young man is concerned (or it could be a job as far as the girl is concerned, too). But the idea of vocational growth means what you do with yourself as an adult.

If in a community we cannot find what we call immediate service to help the visually handicapped youngster, this does not mean that we should stop nor even temporarily discontinue a plan for the child's development. This plan should be carried out by virture of your long range thinking and your long range consideration of the individual rather than saying, "We have reached the end of the road, we can do no more for Johnnie, nothing is available for him, so here we stop." Usually there is something else available for everyone if you look long enough and hard enough and in simple enough places. Let me accent that last point. There is always, therefore, some service or some group of services that are applicable to a youngster's needs. The resource finder, then, continually opens more doors and he builds more rooms in which the handicapped child may live. He makes the child's education and his care and his development meaningful and he puts it in a usable package.

Now that we have introduced what is behind the idea of community resources I think the next thing to consider is just how we can implement community resources and what some of these things are and should be. The guidelines for action probably should be to understand the child's needs and have his goal focused upon what the individual child's potential development should be and this potential development always should be on a level higher than what his current achievement apparently is or what you may think it should be. I believe we should always look toward a little more and a little better objective than we think the child can possibly obtain. This is in all fairness to him because, after all, everyone grows, and some of us grow physically better than we do mentally, some of us grow mentally better than we do morally, etc. Nevertheless, our objective should always be on a slightly higher level than the level the child may apparently reach.

The immediate problem should be evaluated by any organization concerned with the child in relation to his physical, psychological, social, familial and vocational characteristics, and tie with them then, his potential and needs. We must have joint understandings between governmental and voluntary agencies in order to make community resources effective. This is extremely important. I know many communities, including our own in St. Louis, where we are very lacking in the fact that we do not have enough joint understandings in writing between voluntary and governmental agencies, or between voluntary agencies and other voluntary agencies, or between our own governmental agencies. We have evidences in our state right now of one governmental organization supporting a Speech and Hearing program through another governmental organization that has no relation directly to the Department of Education. This confuses purpose, it confuses people and it prevents our youngsters from receiving educational services to which they are entitled. This is one example of a lack of coordination, therefore these joint understandings are most important to make communi resources effective.

Each organization, also, should have clearly defined objectives, roles and goals in terms of either a joint cooperative agreement or what they themselves do. How many times have you called a social agency of any kind, or health agency of any kind, and said, "I have a child that is apparently in need of such and such," and this agency replied to you, "We don't take care of that sort of thing." When you're supposed to represent organizations in favor of the blind and visually handicapped, what do you do? "Well, maybe we take care of children only up to 5 years of age, and we don't take care of you if you were born blind, but if you were handicapped by a freight train splashing cinders in your eyes, we'll take care of you." This is a real exaggeration of my point, but I'm making it for a reason. Many times in securing help for handicapped children, I have called agency after agency, organization after organization and they have given me answers somewhat in relation to what I'm telling you. Or, "We don't do it here," (this child may live in Jefferson County, Missouri) and "We don't do it in Jefferson County because we have spent our money, but you should apply at the State office." And then you apply at the State Office of this organization and say that we have this handicapped child that needs such and such, he is handicapped in the area that you are concerned about, will you give us a hand? "Well, our local society is broke there, and they're still paying the debt to national society." You're frustrated again because no one is able to solve your problem. And it's all because of the fact that they do not have clearly defined objectives and, not only that, they do not have clearly defined realistic objectives in terms of what they can do and should be doing. These objectives have not been published to inform the public, neither have they been given to professional workers like yourselves and myself who are actually plagues our good Superintendent Heltzell is that we have a room for multi-handicapped youngsters and yet the future of this room and the future of the program is in question because selling the idea to the legislature, getting adequate support necessary for assistance of these youngsters, is a very difficult thing to do. Likewise, we have the problem of multi-handicapped youngsters of all kinds, particularly deaf and blind, for which we seem to have a serious problem in getting local community support and local resources in order to be able to set up a program which will serve these children within our boundaries. Therefore we have to seek services outside the boundaries and as a result someone is left holding the "sack." It means that if voluntary agencies do not pinpoint these things for official agencies, if they do not help support action for proper care of our visually handicapped youngsters, the services of the state tend to become institutional. This is not a reflection upon any one state or institution, this is what happens to <u>any</u> organization that sets up any sort of a health, education and welfare program. You become institutionalized within yourself because you are an institution. The Missouri Society for Crippled Children is an institution and if we set up certain patterns, then we become institutionalized in our approach to the problem of the youngster.

Getting back more specifically to the subject, and to bring out the need for community resources, I would like to point out a very simple application that happened to us some years ago in Montana. Many years ago, 1947, the Society began a program for cerebral palsied youngsters in most of the states in the nation and began to give emphasis to the development of this type of community resource. Montana was no exceptio and at Billings, at the Montana State College, we developed a treatment training center for cerebral palsied youngsters. No child was allowed to enter until at least six yearsof age. South of Billings is a reservation, the Montana Indian Reservation at Hardin, about half way between Billings and Sheridan, Wyoming. This reservation is in a very God forsaken area. It's a very barren ground. It's in a valley, if you can call it that. It's a flat place called the Powder River of that part of the country (the Powder River, you know, flows into the Missouri in Montana). We always give our Indian friends the best parts of our country. Then the "stinkers" turn around and find oil on it. We haven't figured out a way to cheat them out of that yet, but I expect we'll get around to it before long.

But in any event, cerebral palsied children are not found very frequently among Indian people. What happens to them I do not know. They may die in infancy because of the rigors of life, or maybe they just don't have too many. I know among people that are less cultured than we're supposed to be, there are less cerebral palsied children than there are among more cultured individuals. I use the term "cultured" liberally, you understand.

This man and his wife had a cerebral palsied child and when he became six they brought him to our Cerebral Palsy school at Billings. The therapists were tickled to death and the doctors were tickled to death because here was a little child that could really respond to treatment and therapy. His IQ was up on "Cloud Nine," somewhere around 125, and apparently the type of disability he had was Athetosis and was not severe so that he could develop quite nicely with proper treatment and training and education. We wanted to take this youngster in and take care of him. We went to the Welfare Department, since he came from a very poor family, and we tried for three days through the Welfare Department to find a foster home for the youngster. Nobody would take him because you remember he was a little Indian boy, and it seemed that the good people up in Billings weren't very favorable toward taking a little Indian child into their home.

Everybody was quite sad. We had to send him back to the reservation. The therapist patted his mother on theback and consoled her. She was quite stoic in her reaction about what all had happened. We gave her instructions for building a stand-up table for her youngster and she tucked these in her bag. She had other instructions to do this and that. We told the mother within about six weeks we would be having the itinerant therapy team come down and see how little Johnnie was getting along. Our itinerant team consisted of a PT and an OT at that time. About six weeks later, sure enough, the itinerant team came down to Hardin and went out to find the home on the reservation. It wasn't difficult to find among the sage brush and a few old cottonwood trees. The therapists looked around for the youngster and his family. Dad, of course, was out trying to make a living. Mother was out in the backyard, if you can call it a yard, an open place which would normally be a backyard, and she was hanging up clothes. The therapists looked all around for the youngster, and lo and behold they found him standing in a hole under one of these big old strong cottonwood trees.

Here he was, standing in this hole up to his armpits, just playing around having the "darndest" time you have ever seen. He was just having a great time. The therapists thought he had fallen into this hole so they rushed madly up to pick up this poor little boy and save him. They looked around and lo and behold, every so often there was another hole around the base of this tree. It seemed that, after they put everything together, Dad had received the orders as to how to build a stand-up table but he didn't have any lumber and he didn't have money to buy any, so he built a stand-down table. Then he was smarter than we so-called white people, he decided to build six stand-down tables and keep his youngster in the shade. So every hour Mother would pick Johnnie up and plunk him down in another hole, keeping him in the shade as the sun moved around.

Then on top of that, Dad had dug this hole exactly the right size as the stand-up table so that the little child had the right support from his arms and his shoulders and was able to play on the surface of the ground which was his stand-up table. He was having a "rip-snortin'" time. He was jiggling around on his poor little legs and developing strength in his heel cords and lengthening them too, which is, of course, one of the first activities toward standing.

The nice thing about it was, the second semester we got a good family to break down and accept this little youngster and then got him into the Billings program.

The thing I'm pointing out is that "people mean," not words. People are the things upon which depend whether you have community resources or not. Community resources begin and end with the parents. This is an example to illustrate that all of us should have the gumption to use ingenuity and not try to be so "darn" smart when we're taking care of handicapped people, but to use the simple plain things in life that we can utilize for our youngsters.

I hope that illustration wasn't too long; but it's a very true one. I followed this youngster for about 15 years and he is in the State

University in Montana now and doing very, very well. He will be far more independent than his Father and Mother ever were, and thank goodness that it worked out so very beautifully.

Community resources begin and end on this basis. Now lets talk for a moment about what we need in the education of blind and partially seeing children in the way of community resources. In the first place, we find that we have a complex problem. We have a more complex problem, for example, than that of providing a child with a brace or providing a child with a single diagnostic service. We have a problem that usually develops, as our previous speakers have indicated, including the problem of possible emotional effects, either in the child or the parent or both. Now these are fortunately, I was glad to hear the good doctor say, very often pseudo in effect and appearance, and I sometimes think that they are more pseudo than we sometimes like to admit. Sometimes we want to make a "federal case" out of some of these things, you know. We pick a child apart and we get to talking about some little old thing that's bothering the "kiddo" and we forget about the child's basic problem. This we should not do.

When we're seeking community resources, the same thing is true. By definition, if we have a child who has limited sight so that he requires a special adaptation or special education of any kind, then he would be classed as a child who would be in need of a community resource. We are not concerned about the incidence of blindness when we talk about obtaining community resources, except when we get to the point where community resources are filled up or when they're patronized by an outside source to the point where they will not take anyone else. We are at that point, I'd say, in the school for the blin

Isn't that right, George? Don't we have about a full house here? If we had an influx of 25 or 30 more children right now, we would have to look for another community resource. This community resource is one that transcends the community itself. It goes throughout the entire boundaries of the state.

The needs of these youngsters are the things for which we are trying to provide. We've got to be very careful with this. In looking for community resources, we have too many agencies and organizations, and professional people in these organizations, that have a tendency to count numbers. We seem to have a great pride, and I'm sorry to say this but some of my co-workers in organizations have great pride, in stating that there are so many mentally handicapped, there are so many blind children, there are so many muscular dystrophies, there are so many post polio, there are so many this, that and the other thing. That's not the point and that will never be the point in fulfilling community resources for children's actual needs. The thing is, "What do they need that will benefit them." Not necessarily, "What does Dad and Mother want," but "What will be worthwhile for this child to help make him the most self-sufficient citizen possible when he becomes an adult?" That is the thing we must boil resources down to.

Just this week, today in fact, I had a school for the retarded write me and ask us for a walker for a handicapped child. This child is also visually handicapped. I immediately called the doctor in charge of the case and I said, "Doctor, what is your recommendation? Do you wish this child to have a walker?" He said, "Absolutely not." Here's a case of a parent making a request for a service, assuming that there is no community resource, so they write to St. Louis to get us to provide it.

But they're making a request for something that will not benefit this child and something we cannot provide simply because it is not ordered by the person who has the legal responsibility to order it and to take the responsibility for that individual's progress. We have to be very careful when we're talking about community resources, so we do not try to obtain community resources on a pseudo basis. This is quite often a tendency.

You may say, "Well my goodness, we have so many post-polios." Of course this is an old story now but let's just use it because it's a good example. The point is not how many post polios there are, but what do these post-polio people need to result in more effective rehabilitation. As a result you arrive at two different numbers.

In 1960 it was my pleasure and privilege to write the report on physically handicapped children for the state of Missouri in connectio with the White House Conference for Children and Youth. I found that quite often, in fact in an appalling fashion, organizations knew nothing about what numbers of people there were or who there were, whether or not they were multi-handicapped or how many times they were being counted by various agencies in the state. For instance, we had a child who was blind, cerebral palsied and hard of hearing. We found out in many cases a child wasbeing counted by three different groups. Sometimes children were being counted four times because in some cases the State Crippled Children's Service was also counting them. Three voluntary agencies were counting: an association that had to do with Deafness and Speech and Hearing was counting, an association interested in cerebral palsy was counting, an association interested in the blind was counting because this child had a visual disability.

To boil down what children need, we must be very discriminating in making this kind of a decision and we must look for the child's true needs. To look for them then, where do we turn? We turn to the four basic pillars of habilitation and rehabilitation, as I've given them to you: (1) what are his social problems, (2) his psychological problems, (3) his educational or vocational problems and (4) his medical or his treatment problems. Put these together to make life worthwhile for the handicapped individual.

For these children we also have the possibility of itinerant programs. Itinerant programs will transcend communities, again in relation to community resources. We will have a carry-over of children who are visually handicapped into the regular classroom situation. Actually, getting children back into the regular classroom is an ideal thing, after we teach them all of the techniques in mobility, the techniques of transportation, the techniques of braille, typing and so forth.

To get the children back into our community and our homes is probably the most important thing we can do. I don't see how anyone can expect any handicapped youngster, regardless of his disability, to be disjointed from his family or community a great number of years and then expect him to go back into the community to make any kind of a living or to have any friends or to have any associates or to fit into the community in any way whatsoever. It just can't be done. We seem to have a sort of rule of thumb: the longer we maintain disability, the longer it takes us to eliminate or to minimize disability. I think that's an old cliche from somewhere down the line, but nevertheless, it still seems to be quite true.

As diagnostic agencies have developed, and they have developed in massive numbers in the past 10 or 15 years, we are having more and more difficulty in sorting out and trying to get community resources. I find, and I can prove this with our referral figures, that in the past 15 years the Missouri Society for Crippled Children has had an increase of about ten times the number of referrals that we had fifteen years ago. Perhaps even a little more than this. I'm giving you a conservative figure. At the same time, the population of Missouri has only increased 2% in this same number of years. The only question I ask, to stop this kind of frustration and to get things for people, is, "What are all of our organizations doing?" We have an organization for every part of the body, what are these people doing? You call an organization up and say, "How about some assistance in this, that or the other disability," and we can get no assistance. Again it boils down to what you, yourself, can do, and your key person goes right back to your family situation.

I would be very foolish to try to tell you what specific community resources are effective in Atlanta, Georgia, or anywhere else. I can tell you about Missouri. I can tell you about this side of Illinois and I can tell you about things that are within reaching distance of this point because I'm very familiar with them. But I do feel that when you're seeking anything for anyone, if you will get together with your school for the blind or with your division of rehabilitation for the blind (both preferably), and the Special Education people in your community, and sit down and talk over the things that you find out as being people's needs, that you'll find the answer to them. This is the way we started our multi-handicapped program at the Missouri School for the Blind. We sat down together and said, "We have children who have the problem of blindness in this state and who are not in school. These children also have other disabilities. What can we do to get these children in the Missouri School for the Blind? What can we do to help these parents?" We conceived this kind of a program just on the basis of getting together and putting this sort of thing together. It wasn't as difficult as it may sound. I think the procedure in the past year has covered something like 28 children in a complete diagnostic and evaluation program and more are coming along all the time.

The thing I'm pointing out is that 28 children in Missouri were once considered to be hopeless, once considered to be outcasts, purely because they had not been diagnosed nor evaluated properly. No one could find a community resource for them until we ourselves got together and solved the problem. You can do it. You can do it just like the Indian father did when he decided he didn't have any money to build an expensive stand-up table and "by golly" he could build a stand-down table. So he's a lot smarter than we are.

Community resources are very elusive, this is the last point I would like to make. They're very elusive because voluntary agencies in particular move quite rapidly and they have a tendency to tell you what they would like to do, or what they're going to do, rather than what they actually do. You come to an organization and you say, "What is your program?" "Well our program is such that we are going to do such and such." There you are again, you are stymied in using that kind of resource simply because it does not exist.

Another thing you have to watch for when you're seeking community resources is to remember that programs interested in research are usually not interested in people. They can't be interested in both. They're interested in research and spend their money for research and this is a valid and a good thing. Nobody is discounting it. But they can't spend money for people if they do research. Usually you'll find heavily oriented research programs are interested in something that you can't quite get your finger on for community resources. This money will be spent in New York or Chicago or some other "foreign" port, rather than in helping solve your program in community resources. I'm prejudiced on this subject and I'm perfectly free to say so. If you have searched as long and hard as I have to get help for hundreds and hundreds and hundreds of handicapped children who desperately need community resources, I think you would share with me very much my attitudes and feelings about the problem. I really haven't much time for organizations that I call up and ask for help for a certain child and then when they tell me that we don't take that age group, or they're too young for us or they're not quite tall enough or their hair isn't the right color, or something as ridiculous, believe me, we get pretty frantic and we go a little farther with our work to develop our own community resources.

WHAT AFFECTS BLIND CHILDREN'S DEVELOPMENT*

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Over the years it has become increasingly clear that the role of the parent of a blind child is of even greater importance than is his role with the so called "normal" child, and that in addition to being a "good parent" there are added responsibilities and problems related to the fact of blindness. The specific nature of these factors has not been well understood and parents have often been faced with conflicting recommendations which have only added to their sense of inadequacy in dealing with a disturbing problem.

Reasons for the lack of agreement among the recommendations given parents are not difficult to find. Few professional people are prepared either by training or experience to give realistic guidance. In addition there has been little by way of sound research to give direction in dealing with the complexities in any given situation. Recognition of these facts led to the development of the Project for Pre-school Blind Children at the University of Chicago Clinics and to continued efforts to carry on the longitudinal study of the research group of blind children with which I have been associated for more than twenty Years.

The Project came about because of the crisis created by the high incidence of blindness among premature babies from causes which no one then understood. Dr. Arlington Krause, Chief of Ophthalmology at the University Clinics, had long been interested in eye conditions among infants and young children and began intensive research on the mounting

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*This is an edited transcript of Miss Norris' informal address. A more formal presentation under the same title may be obtained as a reprint from the American Foundationfor the Blind, 15 West 16th Street, New York, New York 10011.

problem of retrolental fibroplasia. His research interest came to be known throughout the country so that increasingly other doctors referred their prematures who were showing this type of blindness to him for diagnosis and recommendations.

At the time when the problem was first being recognized I was working with Dr. Krause as social worker in his clinic. I had come to Chicago in 1941 expecting to be there for one year only to take some specialized graduate work at the University. I had not intended to take on anything by way of professional responsibilities but it was a time when social workers were in short supply and large demand, so rather reluctantly I agreed to take on some duties in the Eye Clinic as Dr. Krause's social worker. It was at that time that the long range implications of the problem of blindness among prematures were coming to be recognized by the medical staff. It was a shock, however, when Dr. Krause said to me one day, "Miss Norris, what are <u>you</u> going to do about the increasing number of blind babies?" I was on my way home from the office about 5 o'clock in the afternoon. We were still talking about it at 9 o'clock that night. And of course that was only the beginning.

Many of the things that Miss Maloney said the other day were characteristic of our early experience as we began to try to find out what people knew about blind children and what they were recommending by way of treatment. On inquiry we found that in the field of work with the blind the universal assumption was that a residential nursery for blind children at the earliest possible time was the type of recommendation that should be given to a family.

It is probably not surprising that most of the prescriptions for the rearing of blind children prevalent in the 40's still clung to the notion of the residential nursery and the teaching by "experts." If we go back in history to the time when most of the services for young blind children were developing in institutional settings, in the period shortly after the turn of the century, there was comparatively little of our current understanding of the way all children develop and institutional care was unquestioned. Sometimes we forget how rapidly our knowledge has grown about children in general in the last quarter century. In any event it was probably fortunate that as we began to make some investigation of possible resources we found that the Boston Nursery for Blind Children could accept no more patients, that likewise the nursery at Los Angeles had no vacancies, and that there was no other known program of this type in this country. Not having the easy answer of an already established facility forced us to look into other possibilities.

As we considered the problem with interested people at the Clinics it soon became obvious, moreover, that a residential nursery did not fit in with what the pediatricians, the child psychiatrists, and psychologists thought about the way children develop and the type of environment which should be provided for them.

Actually most of the things the Project staff were seeking, in trying to understand visually handicapped youngsters, were increasingly in terms of what was known about all children, and more specifically how specialists in the general field of child development could help us understand children in the particular type of a situation with which we were dealing.

Fortunately, at the Clinics we were accustomed to working very closely with people of many different professional disciplines and from the beginning of the project we were involved not only with the ophthalmologists but with the obstetricians, the pediatricians, the psychiatrists, the psychologists, the nurses, and all the rest of the Clinic team.

I won't go into detail in regard to the medical aspects of the research but I do want to go into the question of the kinds of services we finally came to recognize, on the basis of experience, were needed in terms of help to parents. From the outset, whenever Dr. Krause was seeing a blind youngster, a call would go out on telepage for me and for the head of psychology to come to Eye Clinic. We very soon discovered that, regardless of what we might be doing at the time, it was important for us to try to get over to the Eye Clinic as fast as we could because Dr. Krause would be there waiting for us with a parent and blind child. He would review the situation medically and then say, "Now this is yours. There are no medical recommendations except periodic examinations." And we were expected to do whatever we could to help the parent in terms of planning for the child.

As you can imagine this was a somewhat overwhelming experience, particularly since we didn't have any ready made answers or any specialized resources to which to turn. Fortunately, I think, the doctors wanted to continue to see these children. Dr. Krause himself was very anxious to examine the children at frequent intervals and wanted the psychologist and social worker to be involved on the return visits as well. We weren't very sure what we were doing in those early days but we learned a great deal by the process of trying to understand cases as they came to us. During this period we had no special research program; this was just a part of the daily round of activities. But we soon became aware of the fact that we were dealing with a much more complex and serious thing than could be handled in terms of fringes of time. Someone really needed to get down to business and see what was going on in the life of the blind child.

One of the things that was assumed in the beginning by the doctors, and I think by almost everyone, was that the child who had retrolental fibroplasia was a severely damaged child organically. It was not just a question of an eye condition; the presumption was that he was a seriously brain-damaged child, with immediate commitment to a state institution for the feeble minded as the only realistic plan. I have to say that the first children whom we saw gave all of us very much that impression as they came in. They were such passive, withdrawn youngsters, that one really wondered what could be done to better the situation for them or for the family. But the thing that we very soon found was that the second time we saw the baby and the mother the situation didn't look quite the way it looked the first time. And the third time it looked quite different from the way it looked the second time. And so we began to see that the hypothesis of basic mental defect certainly needed to be challenged.

From the outset the psychologists were confronted with the question, "How do you evaluate, or <u>can</u> you evaluate, the potential of this child?" Fortunately the Clinics had as Director of Clinical Psychology Miss Anna S. Elonen[1] who had had extensive experience with all kinds of children. Miss Elonen very soon concluded that the children were unlike other defective children whom she had seen and believed that we were not justified in going along with a recommendation for commitment. At the same time we knew that in some way or other we had to find ways of helping the parents meet the immediate situation at least. We didn't expect that it was going to be a long term type of thing when we started out; it very soon became apparent, however, that there was need for an intensive period of study on a long term basis of the development of these children.

The search for research funds then began. I'm sure most of you have had some experience with this and know that it is a frustrating and difficult kind of business. A great deal of what we did in those early days was done on faith because we had become convinced that it had to be done so we did it on the fringes of time. Then when we were finally able to get the funds for the longitudinal study, we got much less than we had hoped for. We had hoped that we could get funds that would support a broadly based project which would include medical, social, psychological, educational and other aspects of the problem over a period of time. Unfortunately it didn't work out that way. Dr. Krause had to get funds earmarked for medical research and Dr. Elonen and I began the rounds of trying to get support for a developmental study. We were able by dint of much effort to succeed and as a result we came to be in the very fortunate position of being able to follow the development of a substantial group of blind children over a very considerable period of time.

It is a little hard to talk about dates. The University of Chicago study was reported in <u>Blindness in Children</u>, published by the University of Chicago Press in 1957 as a five year study. A follow-up study financed by the American Foundation for the Blind and the Elizabeth McCormick Memorial Fund was reported in the <u>School Age Blind Child Project</u>, published by AFB in 1961. Actually a good many of the children are now young adults whom I know today in one capacity or another in relation to my present job so that we have had the great fun of seeing what can happen over the years. For example, two of the children for whom commitment was recommended by the doctors, and where it was only the parents who would not accept the recommendation, are now in college! I think that that is worth emphasis, particularly in view of similar recommendations being made for blind children today and the concern over the expectation that a substantial number are mentally defective. There are wider implications also. When we are talking, for instance, about the percentage of children in the general population who are thought to be mentally retarded, when we are seeing many children in the disadvantaged areas who are presenting developmental problems, when we are concerned with social and emotional deprivation as a part of the study of poverty, I am reminded of many things that came out very clearly in the Project study which are now showing up in many groups of children who are not blind.

Still another point that seems to me to be most important is the urgency in providing parents with the right kind of help at times of crises if children are going to develop without the unnecessary secondary handicaps which are unhappily so prevalent in the group of blind children who are approaching or are now of school age. These children are being found in almost every part of the country. I wish that Pauline Moor would comment on this point because I think that the question of the so-called multi-handicapped blind child, the blind child with problems, has particular significance in terms of some of the things that emerged from the Project studies.

I'd like to back up one minute more to talk a little bit about the children included and the methods used in the Project study. Someone asked me the other day if we had a highly selected group at the University in our research Project. My answer was, "We had every blind child whom anyone knew anything about in the Chicago area who could meet the minimum criteria for study which were established. We had youngsters from the most disadvantaged areas to the most highly advantaged groups. We had almost any variable you can name in relation to blind children: racial, cultural, socio-economic, educational. This proved to be a great advantage and I've always been grateful that we had that opportunity.

The second thing to say about the study group is that for intensive study we had discovered on the basis of experience that we needed to know what happened very early in the child's life. So we included in the intensive group only those children whom we were able to observe on or before fifteen months of age. That does not mean that we did not see a good many other children but it did mean that for the purposes of really trying to come to grips with identifying what enters into the development of the blind child, it was important to make the contacts very early. I think if we could have done so we would have liked to include only those children whom we knew at the time the diagnosis was made or at least by six months of age. A good many of the children did meet these criteria. Those of you who saw the film, "Jean",the other night, saw a case in point. We first knew Jean when she was between six and nine months of age.

Our method of study was based on observations by both the psychologist and the social worker at regular intervals, every three months until the child was two and one-half years of age, thereafter at six month intervals. We made home visits, and I can't over emphasize the importance of what we learned in terms of the home visits. One of the things we discovered very early in the project was that the way the child responded in a situation in the clinic might be entirely different from the way he responded in his own home. Or equally important, a home visit was essential if one were trying to see what was happening which either helped or interfered with the child's development. Seeing the actual set-up at home was a primary factor in gaining this understanding. It meant also, of course, that you had an opportunity of knowing parents in ways that you might not otherwise have done. In any kind of a research project based on direct observation there is inevitably the question as to whether or not the research is "objective" in terms of the fact that your being in it in itself modified the situation to some extent. It can't help it. As one means of consciously attempting to meet this issue the Project accepted the responsibility for the counseling of parents so that at least the staff would assume responsibility which would relate directly to the study objectives. Also, so far as possible, the staff would know essentially the kind of philosophy which was the determinant in any individual situation.

Making meaningful observations is a skill many people find difficulty in developing. Or, to put it another way, they have little opportunity or encouragement to develop it. One has to learn how to observe and to see details that may not appear to be directly related to what is going on at a given time. When you are in a situation you are identified with it completely in terms of the moment; but then later you have to reflect and evaluate what you observed, and, for the record, note how it seems to add up and the questions that it poses. Certain things emerged from staff observations very early in the project. The psychologists had set themselves the task of trying to get more adequate developmental norms because no one really knew much about how a blind child could be expected to develop. No one knew very much either about what one could expect of a premature, even one without any identified physical handicap, and the majority of children in the research group were prematures. The study, however, was not limited to the retrolental group though a large proportion of the children were so diagnosed. But in spite of all the difficulties, the long range purpose of the psychologists remained to get a better basis than then existed for evaluating a given blind child and making recommendations for him. Social workers and psychologists together defined other objectives in terms of what contributes to the optimum development of the child or what stands in the way of his progress. Better understanding of these factors could be useful as one tried to help parents meet the individual needs of their own blind child.

Certain things, as I have indicated, emerged rather early in the game. One was that the general expectation that the blind child was going to be slow or at least slower in his development than sighted children was not borne out. We found essentially the same wide range in the age level at which the mastery of developmental tasks was accomplished as one might have expected to find in any other group of children which was as diverse as this one was. Differences, sure, but the expectation that because the child was blind he was going to be slower proved not to be true. This in itself was a very important thing, in part because this expectation usually meant that the youngsters were treated as if it were true. The theory became the basis of a self-fulfilling prophecy in a situation in which the youngster was not given the kind of build up of opportunity and experiences for which he was ready. Too often the point where the youngster was set to go was missed because no one was smart enough to recognize the fact that he was telling you, in every way that he knew how, that he wanted more opportunities than he was having, that he wanted to pull himself up, for example, or that he wanted to do this, that he wanted to do that. When he was given the opportunity, sometimes very surprising things happened.

I can't tell you how many times the staff had a telphone call from a parent not too long after they had seen the child, saying something like this: "You know you just can't believe all the things that Jean is doing since the last time you were here. I don't understand. What did you do?" Obviously the staff did nothing except perhaps to give the mother a little bit of recognition of what the youngster was trying to tell her and to give her some confidence that she was on the right path, encouraging her to believe that she could do the things the child needed since the child did have a tremendous capacity on his own to develop. I think if I ever learned to have confidence in the capacity of human beings to develop it came during this period when we were seeing many blind youngsters and their families. Even when situations appeared to be unfavorable, somehow or other the push toward normalcy, the integrative capacity of human beings, given even a little bit of recognition and respect, became evident. This to me is the most encouraging thing that one sees. Certainly there are many grim situations where one wonders what one can do that will be of help. Many times it isn't doing anything specific; it may be only the point of view, the perspective, the confidence that somehow or other one is able to put into the situation that frees the mother and the child to move ahead. I come from the Eastern part of the country and sometimes say to myself some of the things I heard my New England grandmother say. For example, I have sometimes thought that the most important role I can play is that of being "an anchor to windward." Sometimes I think of it rather in terms of gardening and use her expression "a green thumb;" there are aspects of each that are not easy to put into words that go into this kind of supportive relationship. But however one describes it, giving a child a favorable opportunity to develop is basic to his satisfactory growth. This usually comes about when the parents are bolstered in their confidence in their ability to provide the necessary ingredients.

I have already implied a very important conclusion or hypothesis from the study; namely, that blindness in and of itself is not the determining factor in the child's development. There were blind children in the group who were developing extremely well and were doing essentially everything that sighted children of their age level were able to do. There were blind children at the other extreme who were doing very little. We tried very hard throughout the study to see if such differences could be explained by the degree of vision, or by the type of blindness, or some other physical factor. No consistent relationship was found and we reached the unexpected conclusion that something other than blindness was the determinant. I think, however, that this hypothesis has often been misinterpreted or misunderstood. To say that blindness is not the determining factor per se is not at all to ignore the significance of the physical handicap. It only makes it, in one respect, more difficult to understand and to deal with because you are immediately involved in the whole complex of personal relationships, social experiences, and the imponderables that almost defy definition.

Actually the effect of blindness in the pre-school period appears to be much more the effect on the adults who have a close relationship with the child than on the child himself. We found that when a parent, or other adult close to the child by some fortunate combination of circumstances was not thrown by the child's blindness and was able to relate to the child as a child, and do the kinds of things that we hope all parents will be able to do for their children, the blind child was able to respond and progress. This is not to minimize the fact that the blindness was an added problem for the parent. There is no question about it, the handicap puts a tremendous added burden on the family. Neither is it to minimize the fact that the developmental tasks of the child are made more difficult by the lack of sight. As a corollary, society has a tremendous responsibility for providing the kinds of services and understanding which are going to deal with some of these complicating factors so that the situation is, in general, a favorable one for both parent and child.

If we turn now to Project experience with some of the children who have had serious developmental problems, I would guess that if we really knew enough to be able to identify and put together the significant factors in the early history of these children, we would find that they fitted into the kind of thing I am talking about, where, for some combination of circumstances, the situation was unfavorable for the child's development. I suspect that in a great many cases there were, and even now are, some professional people saying with great assurance that you are dealing with basically mentally defective children. In one sense I think this is a sort of unfortunate turning around of the principle which I tried to state earlier, which was that the blind child could develop well, if....We forget the "if" and when we see a child who hasn't developed well or who has serious developmental problems, we tend to make certain assumptions. I think all of you will have had experiences of your own to illustrate this. The two assumptions that I hear most commonly are: first the blanket assumption that if the child has serious problems there must be an added something "wrong" with the child, a related medical condition or organic defect. I do not mean to rule out the possibility that there may be such a defect but the blanket assumption is rarely justified. The second one is usually, "If there isn't another defect to explain the child's difficulties, what's wrong with the parents?" This too is probably equally unjustified. The much fairer question is "What is wrong with the community? What is wrong with us and the kinds of services that we have provided or failed to provide, in the things that we have not done, that have contributed to the severity of the problems?"

There is one particular type of developmental problem that I hope Miss Moor will comment on later from her experiences. We have observed that a good many of the children who are coming up to school age and who do not fit into the regular school program are children who have severe problems in communication. They may be children who have no speech or they may be children who, so far as one can tell, do not use speech in a meaningful fashion. There is not time to go into any extended discussion of that specific problem but I would merely like to throw out the suggestion that I suspect that in very many cases you have a child who has been bombarded with talk at some early period in his development and where speech has loomed as terribly important to the family or to the psychologist as an indicator of mental ability. This pressure on the child to talk is understandable since the level of verbal communication is recognized as one of the major tests of psychological ability. This type of child is going to take a great deal of further study before we can speak with sureness about his difficulties. My own belief is that we will get help on this type of problem mainly from psychiatrists and others who are working with severely disturbed children such as the so-called "autistic" child, the "schizophrenic" child, and so on. From our experience the relationship with blindness seems largely coincidental since we found that the problem could be pretty definitely related to the kinds of experiences which the child may have had at crucial periods in his development.

Just one other thing that I want to take time to emphasize and that is the question of <u>teaching.</u> I am talking now about pre-school and the very early experiences of the child. The recognition that all of us have that the blind child is going to need much help in understanding his environment means that all of us will be thinking about how we are going to give him the necessary experiences at the appropriat times to encourage his optimum development. How are we going to help him learn and teach him to do the things that are important? Emphasis in all of the early material on the young blind child was on teaching by the expert. If you review some of the publications of the Boston Nursery, for example, you will find the philosophy that it is the teacher who teaches by means of special techniques related to blindness. Take walking, for example. I remember vividly the pictures illustrating the technique. In one the teacher has a child standing with his feet on her feet and she is literally propelling him ahead as she, not the child walks. I personally suffer almost as much over the recommended technique of teaching the blind child to chew by having the teacher manipulate his jaws with her hands. Perhaps I'm enough of a non-conformist myself to know how I would react to that type of handling. But there is mounting evidence that many of the children who are presenting problems are children who have become resistant to learning because of some such unfortunate experiences from well meaning adults along the way.

We have much to learn in terms of how we can go back and overcome some of the results of early mistakes, and of the time which it takes to regain the confidence of a child enough to help him get the sense of his own person and to develop an ability to control situations constructively so that he does not have to control them in destructive ways. These youngsters who are problems to us control themselves in relation to their environment, make no mistake. They will continue to control their environment and everyone around them in one way or another unless we gain better understanding of how to help them respond differently. Many times we have fallen into the trap of setting up the kind of situation where we feel utterly helpless because the child seems to have all the cards. He really does, you know. You can't make a resistant child talk, you can't make him eat. I don't know any adult who can really make a child do anything which he does not wish to do. Perhaps that is my strong bias but the case histories of many of these children support the thesis! With this in mind, I have a particular interest in a remark that I heard Dr. Benjamin Spock make at one time when someone asked him how to teach a child to walk. Dr. Spock's reply was, "You don't teach a child to walk. When his nerves and his muscles and his spirit are ready, you can't stop him." This is the kind of thing that is very hard for most of us as adults to learn but I think that Dr. Spock has said in deceptively simple terms what we must learn if we are to understand how children grow, all children, and if we are to help parents with what appear to be the special problems of the blind child.

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--Michigan's Summer Program for Multi-Handicapped Blind Children, by Anna S. Elonen and Sarah B. Zwarensteyn, New Outlook for the Blind, March, 1963.

--Diagnostic Evaluation and Treatment of Deviant Blind Children, by Anna S. Elonen and Albert C. Cain. American Journal of Orthopsychiatry, Vol. XXXIV, No. 4, July, 1964.

--Appraisal of Developmental Lag in Certain Blind Children, by Anna S. Elonen and Sarah B. Zwarensteyn, The Journal of Pediatrics, Vol. 65, No. 4, October, 1964.

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LIAISON WITH AND REPORTING TO SCHOOLS

by Dr. Randall Harley
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Some parents and pre-school workers are concerned about proper placement of their children in the best possible school. I am going to talk to you a few minutes concerning this placement and try to supply you with some information that will be helpful to you in making this decision.

"The American Foundation for the Blind recognizes three types of education for blind children of school age:

1. Education in a public or private residential school for the blind.
2. Education with the sighted in public or private schools with a resource or special class teacher available during the entire school day.
3. Education with the sighted in a public or private school with itinerant teaching service available at regular or needed intervals."

It is realized that the changing needs of the blind child require flexibility which will enable him to move from one type of program to another. Some states such as Oregon provide this flexibility so that a child may easily move from one type of program to another.

It is suggested that placement of the visually handicapped child into the educational setting best suited to his needs requires a pooled opinion of specialists in order to arrive at the best decision. It would be a grave injustice to place a blind child in an educational setting that is being maintained by standards that are low in comparison with those held for sighted children in the same area.

Parents living near or in metropolitan areas may find one or several types of programs available for their children. Five types of day school programs may be found around the country:

1. The self-contained classroom - This type of program was developed first in the day school development and has largely been replaced by other types. It consists of a self-contained classroom in which all of the children remain with one teacher a majority of the school day. It is rapidly becoming outdated because of its segregated program.

2. The cooperative plan - This plan is one in which the visually handicapped child is enrolled with a special teacher in a special room but goes to the regular classroom for a portion of his school day. The special room is his homeroom and the special teacher plans his program in cooperation with the regular classroom teacher.

3. The resource room - The resource room is a plan calling for enrollment of the child in the regular classroom. The regular teacher plans his program with the advice and assistance of the special teacher as needed. The special teacher helps to provide any necessary specialized instruction, materials and guidance or specialized services that may be required. Her room is usually called the resource room.

4. The itinerant teacher plan - Provision is made for enrollment of the visually handicapped child in the regular class as his homeroom. The itinerant teacher visits the school regularly or as often as she is needed to supplement the work of the regular classroom teacher. She provides individualized instruction, offers consultation, furnishes special materials and equipment, and develops or coordinates special services such as reader service or transcription service.

5. The teacher consultant plan - The teacher consultant is very similar to an itinerant teacher. The child is enrolled in the regular class as his homeroom. The teacher consultant visits the school to provide special services that may be needed. However, she devotes more than fifty per cent of the time to working as a special consultant with the teachers and less than fifty per cent of her time is given to working directly with each child. This program requires the greatest independence of the child and probably provides the best opportunity for maximum integration of the visually handicapped child into the regular school program.

The residential school program for blind children was the first type of educational program for blind children. I won't attempt to describe the program since most of you have already become acquainted with the residential school through your visit the past days at the Missouri school. Anything that I could say would be very meager compared to information obtained from your observation of the school and your conversations with the administration and staff.

Some parents are interested in determining the proper placement for their child - a day school or a residential school. Berthold Lowenfeld, the former superintendent of the California School for the Blind, has suggested that the residential school would be best for the following groups of blind children:

1. The first group includes those children for whom no local services are available. A few years ago the residential schools served the vast majority of visually handicapped children. Today, due to the urbanization of our society and the rapid expansion of special educationa services for visually impaired children in day school programs, the

majority of these children are being served at home in their local school system. However, in many parts of the country, such as the South, most children are attending residential schools. Children living on farms and in small communities usually have no choice in programs, and they board at special schools because no other services are available to them.

2. Another group according to Dr. Lowenfeld includes those children who have poor home environments. He mentions broken homes, homes where the atmosphere for normal growth and development is poor, and homes that have lost one or both parents because of death or other reasons. Some residential schools have many partially seeing children, even some reading small print, who have been removed from poor home environments.

3. A third group includes those visually handicapped children who have one or more additional handicaps. This group would include such children that because of multiple handicapping conditions are not able to succeed in day school programs because the programs have not been designed to meet their needs. These children may be emotionally disturbed, orthopedically handicapped, mentally retarded, deaf, or have a multiple of handicapping conditions in addition to visual impairment.

4. A fourth group, according to Dr. Lowenfeld, includes children whose parents believe that the residential school is a better place. Parents may feel that the residential school offers a better program than the local day schools provide. Many of these parents may live near or be able to conveniently move near the residential school in order to keep their children at home.

The residential school can offer certain advantages to the child such as providing services from a pool of trained specialists, as the ophthalmologist, pediatrician, medical specialists, psychologist, social worker, and special teachers. The residential school can also provide a more specialized curriculum with facilities and equipment to fit more closely the needs of visually handicapped children. This does not mean that the day school cannot provide these services, neither does it mean that the residential school always offers superior specialized services. The consolidation of visually handicapped children in one school helps to make these services available more easily.

The day school can offer certain advantages such as making it possible for the child to remain at home within his family group. The education of the visually handicapped child with sighted children in public or private day schools is based upon a philosophy that children have a right to live and to develop in the family and local community during their education, and that the family and community have an obligation to provide him an opportunity. There are many advantages to this arrangement that are very obvious. A few children in some residential schools may not get to visit their parents at home except at Christmas and summer vacation. Another advantage offered by the day school is the opportunity for integrating the child with his sighted peers in his community. Children may learn to live and participate in activities with sighted children who will be their neighbors when they complete school.

The decision of placement of a child in a residential or a day school program will ultimately be a decision that must be made by the parents.

This decision should be made considering the knowledge of the special needs of the child. Advice and information can easily be obtained from the schools under consideration.

You might want a little information on some recent developments in day school placement of sighted children. John I. Goodlad has written an article that appeared in a recent issue of Saturday Review, entitled "Meeting Children Where They Are." He suggests that schools too often make the child fit the school when really the school should be designed to meet the needs of each child. The proper question to ask upon enrollment of a child in school is not, "Is Jimmy ready for school?" but, "What is Jimmy ready for?" He suggests that an ungraded school is the answer to many of our problems in placement of children. Old traditional grade level concepts have been removed in many new modern schools. The idea is to design a program to meet the needs of the child, not to make the child conform to school requirements and standards. The old chronological age concept has been changed in these schools. Children are grouped together in clusters according to interests and maturity. The principle idea is to do what is best for the child at his particular stage of development, not what is best for the school. For example, children in one school go through three board levels of function and expectation. The first level enrolls children from under four to over six. The primary function is to develop a sturdy, wholesome, self-concept - not reading, writing and arithmetic or readiness for reading, writing and arithmetic. Children are not expected to meet standards of excellence in academic subjects according to the traditional grade level concept. Parents of pre-school visually handicapped children might be interested in encouraging schools to adjust to the needs of their children. The latest movement in providing service for multiply handicapped blind children is illustrative of this adjustment.

In "The Folly of Overplacement," an article by Jack Harrison Pollack in a recent issue of the NEA Journal, Pollack stated that overplacement is probably the greatest single reason for children hating school, failing, dropping out, and eventually becoming delinquent. He reviewed a study by Gesell Institute of Child Development in New Haven, Connecticut which appears in a recently published book, in which primary blame was placed upon ambitious parents who set unreasonable goals for their youngsters. "The earlier a child is admitted to kindergarten or first grade, ready or not, the happier some parents have been." It has been the practice in most public school systems to base school admission on chronological age. There are differences from state to state and system to system concerning age requirements. The general practice seems to be based on a belief that at a certain age all children have reached the same stage of development. However, the Gezell investigators discovered that not all five-year-olds are ready for kindergarten and not all six-year-olds are ready for first grade. They suggest that children should start to school on the basis of how old they are performing. In other words, a child who is six may be ready for kindergarten type experiences. An eight year old may be ready for activities commonly associated with the first grade.

The results of this study confirmed clinical findings that if children enter school on the basis of age or intelligence alone, more than half will be overplaced not only at the beginning of school but also in later years.

Evidence from this study indicates that many children are imprisoned in a school atmosphere that is not conducive to their best interests. Children sense early that they are failures. This feeling of failure can be carried with them throughout school and later life and some may become emotionally disturbed with all of the pressures put upon them to achieve too much too early by well-meaning parents, teachers or administrators.

In order to secure the most suitable placement for each child in a day school or a residential school program, a team approach offers many advantages. This method provides for close cooperation of various professional people in planning a program for each child according to his special needs. For example, a team planning a day school program might consist of the ophthalmologist, special teacher, regular teacher, principal, school nurse, psychologist or counselor, pre-school worker, and a supervisor or director of special education. The team in the residential school might also include the houseparent or houseparent director. Plans for the multiple handicapped visually handicapped child might include such specialists as the psychiatrist, pediatrician, speech therapist, audiologist and physical therapist.

This team may pool together information in their areas of specialization and use this knowledge as a basis for making plans for a program for the child. The group will need adequate information before planning can be effective. This information is suggested in Itinerant Teacher Service for Blind Children, by the American Foundation for the Blind. It includes the following:

1. Medical history - The medical history includes reports from the ophthalmologist, pediatrician, and, in cases involving multiply handicapped children, the neurological evaluation and reports from any other specialist that may be needed.

2. Early social history - This includes such information as history, group experiences, nursery school attendance and family background information.

3. Family attitudes - A home visit may provide valuable information concerning the attitude of the parents toward the child and other members of the family.

4. Psychological appraisal - The Hayes-Binet Test is especially designed for use with young visually handicapped children. Sometimes the Maxfield Buchholz Social Maturity Scale for Blind Preschool Children is used to obtain information on social maturity of the child. This includes valuable information on self-care, communication, dressing, feeding and social aspects.

5. Other special reports as needed - A speech and hearing evaluation, and reports from any specialist that has been working with the child due to special multiple handicapping conditions, may be needed.

6. Previous nursery school experience - Information from previous teachers or a visit to a nursery school by the future teacher of the child can provide valuable information.

The composition of the team with the type of information needed will vary from child to child and from system to system. The team work approach certainly can help provide a more meaningful program for each child and cooperative planning is essential in securing the best possible placement in school for visually handicapped children. In closing, I would like to remind you that Elizabeth Maloney, our first speaker, mentioned how far we have come in such a short time in research and knowledge concerning needs of pre-school visually handicapped children. I would like to show that, on the other hand, there are many ideas and beliefs concerning these children that are still being followed today. You may not agree with all the recommendations in the following report, but many of the ideas have been presented in various forms by speakers in this conference.

How Shall Parents Manage Their Blind Children in Their Early Years at Home, and How Bring Them Up?

Taken from:

Twenty-Ninth Biennial Report of the Trustees and Superintendent of the Tennessee School for the Blind to His Excellency the Governor and to the Fifty-Second General Assembly. January, 1901.

If you have a blind child consider that God has given it to you to be tended with unusual love and care. If you give it proper care and it lives to grow up, it will be a capable and happy human being, who will fill its place in life and will bring comfort to you. But, if, on the contrary, you neglect or spoil your child, it will then be a poor bit of humanity, a burden both to you and to itself. Hence attend to the following rules:

1. Treat the blind child exactly as if it were a seeing child, and try as early as possible to make it put its body and mind into action. As soon as it begins to use its hands, give it toys to play with. Talk to it, sing to it, and give it toys that make a noise, to attract its attention and arouse its mind.

2. Teach the child to walk at the age when seeing children learn.

3. Do not let the child sit long in one place alone and unoccupied; but encourage it to go about in the room, in the house, in the yard, and, when older, even about the town. Teach it to know by touch all objects around it.

4. As soon as possible teach the child to dress and undress, to wash itself, to comb its hair, to take care of its clothes, and, when at table, to use properly spoon, fork, and knife. A blind child can do all these things as well as a seeing child; but you must give it much practice in doing them, because it cannot learn by observation.

5. Watch carefully the child's personal appearance. It cannot see how others act, and so readily acquires habits which are disagreeable to its companions. Some of the most common mannerisms of blind children are rocking the body, twisting the head about, sticking the fingers into the eyes, distorting the face, swinging the arms, stooping and hanging the head in walking, and bending over in sitting. As soon as you observe such practices in your child you should make a vigorous attempt to break them up, for, if they once become habitual, years of schooling may be unable to overcome them.

6. Permit the blind child to play as much as possible with seeing children, and to romp often with them out of doors. Frequently take the child walking, and direct it in some simple physical exercises. If it is obliged to sit still, you should at least give it balls, pebbles, blocks, a doll, a harmonica, or such other toys as appeal to touch and hearing.

7. If you would inform your child of the world about it, you must let it touch all the objects that you can get at, and must teach it to

appreciate space and distance by actual measurement. To cultivate its sense of touch, let it handle familiar objects, like different woods, plants, and coins.

8. Allow the child to take part as early as possible in household duties. Allow it to string buttons or shells; to shell or pick over beans, peas, or nuts; to clean furniture and kitchen utensils; to wash dishes; to grind the coffee; to peel potatoes; to gather the fruit in the garden; to feed the hens, doves, dog, cat, and other domestic animals. You can always occupy the child pretty well in easy handiwork, such as winding yarn, braiding the hair, and in coarse knitting.

9. Speak to your child much and often; for, since it cannot read the loving care which is written on your face, it has special need to hear your voice. Ask the child frequently what it hears or feels, and induce it to ask many questions as to what is going on around it.

10. Take care what you say before your child; for the blind child is more attentive to all which it hears than the seeing child is, and for this reason retains it better.

11. When in the presence of your child never indulge in expressions of pity for its blindness, and suffer no one else to do so. Such expressions can only discourage and depress the child. Rather seek to encourage it and to keep it engaged in happy activity, in order that it may strive cheerfully and courageously to be independent later in life, and to do without external consolation and assistance.

12. Give the child occasion to exercise its memory. A good memory later will be found invaluable. Have it to commit to memory such proverbs, short poems, and stories as it enjoys.

13. The blind child's moral and religious nature can be developed just as early as the seeing child's.

Translated from the Report for 1893 of the Private Institution for the Blind in Linz, in Upper Austria, by Edward W. Allen, Principal, Pennsylvania Institute for the Blind, Philadelphia.