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ABSTRACT

The eight major papers from the Workshop on Diagnosis and Evaluation of deaf-blind children focus upon the roles of various professionals who may be involved with deaf-blind children at the diagnostic stage. Topics covered in the role of the pediatrician in diagnosis and evaluation of the deaf-blind child, the role of the ear specialist (otolaryngologist or otologist), the ophthalmologist's role, audiological evaluation of the deaf-blind child, psychoeducational assessment, speech and language assessment and development, the role of physical and occupational therapists, and the role of social work in assessment of the family and crisis intervention procedures for counseling parents of deaf-blind children. Also included in the conference proceedings are the reports of discussion groups focusing on the papers' topics. (KW)

DIAGNOSIS AND EVALUATION OF DEAF-BLIND CHILDREN

Workshop Proceedings
February 17-18, 1971

Mountain Plains Regional Center
For Services of Deaf-Blind Children

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C O N T E N T S

INTRODUCTORY REMARKS

TO

PROCEEDINGS

Donald F. Moriarty
Project Coordinator

The purpose of this Regional workshop on Diagnosis and Evaluation is twofold:

(a) to give the practitioners from the various disciplines in the major diagnostic centers of our Region the opportunity to share experiences and problems they have encountered in fulfilling their evaluative procedures, and,

(b) to develop standardized procedures and reporting forms, to whatever extent is practical and feasible, so that information can be gathered and interpreted in a somewhat consistent manner throughout the Region.

In the original proposal submitted by the Regional Project to the Bureau for Education of the Handicapped of the United States Office of Education it was planned that one diagnostic center would serve as the Regional Diagnostic Center for evaluation of all deaf-blind children from the six states. Some states have expressed the desire to do their own diagnosis and evaluation and the John F. Kennedy Center of Denver, originally planned as the Regional Diagnostic Center, has decided that this plan would require more staff and time than their facility could devote to just deaf-blind children. It is agreed by the diagnostic centers in most of the states of the Region, however, that true sharing of experiences, knowledge and skills in a cooperative effort, a Regional approach to diagnosis and evaluation of these children can be developed.

We have brought together here outstanding practitioners in the major areas of diagnosis and evaluation of these children, many from within our Region and some from diagnostic or educational centers in other regions who have had a good deal of experience with the type of child who concerns us here.

We are also hopeful that as the various disciplines present their papers and make their consultative contributions, we will all recognize the necessity for comprehensive evaluation of these children and for evaluations which will culminate in a composite of the findings into recommendations and prescriptions which will allow educational and social programming for these children on a meaningful and effective basis.

THE ROLE OF THE PEDIATRICIAN

IN

DIAGNOSIS AND EVALUATION OF THE DEAF-BLIND CHILD

David C. Chambers, M.D.

I believe that you are all familiar with the consequences to a child born of a mother whose pregnancy was complicated by maternal rubella. A great number of these pregnancies are extremely early when the virus of rubella attacks so that many of the young women are not even certain that a conception has occurred. The disease in the mother may be subclinical or extremely mild and actually go unrecognized. Many of the mothers have reported that they had thought that the rash was either due to an allergic phenomenon or nervousness.

Since the onset of the rash denotes a height in the viremia, little if anything can be done medically to prevent the teratogenic effects of the virus.

Since there is now considerable concern in the management of the deaf-blind child throughout the nation, I am certain that you are all aware of the multiple congenital abnormalities that may be present.

The well-known triad of cataracts, sensorineural hearing loss, and congenital heart disease has now been supplemented by innumerable other abnormalities that statistically have been recorded as more and more of these children are seen with our present knowledge.

Practically every system in the body has been reported involved at some time or the other. In fact, the entire developmental process of the infant becomes affected.

It is the extremely rare case when the pediatrician is called by the obstetrician and is alerted that a young mother is giving birth to a rubella complicated pregnancy. The more commonplace situation is that the pediatrician is called to see a low birth weight child with perhaps early jaundice and a rash which invariably is that of purpura. Respiratory distress by itself or being complicated by congenital heart lesion with congestive heart failure early in the neonatal period may certainly present an additional complication and at times even be responsible for added damage to the child. By this I mean the ever present danger of cerebral hypoxia with resultant central nervous system damage and serious prognosis.

The virus of rubella causes enough damage to the child without the addition of neonatal complications resulting in hypoxia or anoxia to the brain. We do, however, know that the brain is sensitive to the virus and in a number of cases a residual viral encephalopathy may persist which creates further problems in the child's development and certainly one would be suspicious at this time in spite of the sensorineural hearing loss that additional "language problems" are an end result of this viral encephalopathy.

The most immediate thought of the pediatrician is, of course, the cardio-respiratory system as far as management for proper oxygenation, pulmonary ventilation and a heroic attempt at prevention of cerebral hypoxia. I am certain that it is for these reasons that often times a very critical sensorineural hearing loss is overlooked by the pediatrician and the presence of early cataracts may also be placed secondary in their mind.

Since the lesion most commonly seen in the congenital heart disease with these children is patent ductus arteriosus early cardiology consultation is indeed necessary. Prior to that time proper pulmonary ventilation and on occasions the use of digitalis for congestive heart failure becomes mandatory.

In the majority of major communities very adequate cardiology divisions are available and as indicated necessary surgical techniques for ligation of the patent ductus can be carried out. In smaller communities where an infant presents with a congenital heart lesion requiring surgery, transfer to medical centers would seem mandatory.

To return again briefly to the presence of the congenital cataract and its early diagnosis, it would not seem right for the pediatrician to miss this important and vital aspect of the triad of rubella babies, but again with the presence of silver nitrate within the eye and/or Penicillin Ointment with a small premature or low birth child who is jaundice with purpura, we find it is not unusual that these cataracts are not early identified. It is embarrassing to be contacted by a new mother and/or father and even worse by the grandparents with a message to your office that there is something white in our baby's eyes. Certainly, at the four to six week check-up, positive identification may often be had and even if the pediatrician is not thinking of congenital cataract, he most certainly would be fearful of a presenting malignancy and for that reason immediate ophthalmological consultation is in order. At that time the role of the pediatrician becomes critical and reassurance to the young parents becomes an ongoing process.

With these major problems behind you the pediatrician tries to relax and yet again may become less alert to the presence of a bilateral sensorineural hearing loss.

It is well established and documented that the most common congenital abnormality in a rubella syndrome is that of a degree of involvement

of the eighth nerve with a resultant sensorineural hearing loss. It is also known that the longer that this disability is ignored, the greater the educational problem becomes. It is not uncommon to evaluate multi-handicapped children at age four who have had a known sensorineural hearing loss and have never had the benefit of a trial of instrumentation.

For some reason the cataracts always get operated on, sometimes early and sometimes badly. Postoperative aphakic lenses are usually always prescribed and, hopefully, worn by the child. We have found that the majority of these children even though legally blind with visual acuity correctable to less than 20/200 have considerable residual vision that allows them to manipulate their environment visually inspecting some objects close to their eyes and recognizing familiar faces. It is the rare rubella child that is completely blind without even residual light reception and there are many who being under proper ophthalmological management have good residual vision. I am certain that the ophthalmologists on this panel will go into the management of the unilateral cataract. Let me say at this time that it continues to be common to find residual auto-oculo stimulation, photic stimulation, and certainly attraction to light source. In fact, in the pediatric evaluation of a preschool age child who has significant visual handicap due to bilateral cataract having been surgically removed, we attempt to utilize light source in holding the child's attention while evaluating another part of his anatomy. It is often time feasible in a small, somewhat irritable and uncooperative rubella child to adequately evaluate the cardiac status while the mother or the nurse attracts the child's attention with a light source.

Let me again emphasize that regardless of what discipline you may be involved in, if you suspicion that a youngster has a hearing loss, bring it to the attention of the parent and/or call their pediatrician who, of course, may be embarrassed, but thankful at trying to get an early hearing age since this will become so critical in his developmental years.

I am not going to talk about the skeletal or bony changes that are present in many infants with rubella syndrome; they are of more didactic interests and may be seen on X-ray. They usually do not cause any residual difficulty with the exception of a personal patient who happened to be an orthopedist's son with rubella syndrome who presented not in heart failure, not with cataracts, not with a hearing loss of any significant degree, but with rather a swollen knee in the newborn period and, of course, our management was that of a septic or infected process initially. The course was quite protracted and of course I missed the early diagnosis of the hearing loss.

With the major abnormalities being managed, it is important to watch the motor development of these children and we find that there is a degree of hypotonia present in a great number of these children. Only a few seemed to present with any residual spasticity of the extremeties, and these we feel are those infants that have suffered secondary cerebral

hypoxia and present more as a usual cerebral palsy child with multiple handicaps. Ambulation is, of course, delayed; and, yet, I believe that we all can predict that the rubella child will ambulate; he will require some early assistance because of some concurrent balance difficulty. And, again, it is the rare case who is not ambulatory by age four or five years.

Probably of paramount importance during the early developmental stages of these children continues to be the constant adult care that is necessary within the home. When at all possible, concentration on activities of daily living to the best ability of the child, taking into consideration his physical handicaps must be emphasized. Independence in basic skills is at times the primary goal in their habilitation.

Now it would seem important at this time to differentiate the role of the pediatrician in regards to the actual chronological age at time of the diagnosis and evaluation.

I have tried to cover the early pediatric infant management which is indeed medically exciting and life-saving at times, but now I think that it is important to speak somewhat on the evaluation of the deaf-blind child in the preschool stage of development.

In the majority of cases, most of these children and parents have sought medical services in various areas including medical centers, highly qualified medical specialists in the community. Their ophthalmological care may be at UCLA, their audiological and otological care at Children's Hospital which is a branch of USC, hopefully, their cardiac status has been followed at one of the two institutions. The family pediatrician may, however, be miles away from these centers, however, finds it mandatory to pull together the pertinent information and act as the liaison with the family regarding their multi-handicapped child.

On the other hand, we have the pediatrician that may have the opportunity to work in a multi-disciplinary approach to the evaluation of the deaf-blind child, which, of course, is most probably the ideal method of diagnosis and evaluation and does not go without some pitfalls.

The primary question must be answered as to why is the parent bringing their child to a diagnostic center or a multi-disciplinary diagnostic team for the evaluation. The most practical answer at this time would be to apprise the child's capabilities and potential for an educational program available within the community. Usually, their acute medical and surgical care has been managed and period followup so the question at the time of this particular evaluation would be what is the medical status of the child and what are his capabilities at the time of the evaluation.

Again, probably the most vital consideration that the pediatrician can give to the other disciplines during the evaluation would be the cardiac status and physical capabilities of the child. Answering questions

such as, is the status of the heart compatible with a day's program in education? Does the child fatigue easily because of the congenital heart lesion? To what degree can physical activity, therapy, and play activities be utilized without overtaxing a heart problem?

Knowing that the cataracts have been surgically removed and prescriptive lenses prescribed, an estimate of the residual vision ability of the child can be had in various methods. Hopefully, the child is ambulatory at the time of the examination, one can determine whether the child manipulates his environment safely. Is the child capable of picking up various size objects at various distances from the face. Many of these children have significant residual vision and are capable of many more things than one would imagine since they have been labeled in the past legally blind. One can estimate whether the residual vision is better in one eye as compared to the other and this would allow the teachers to take advantage of this factor. There is truly no such thing as a pure deaf-blind child. The residual vision on these children varies a great deal and certainly, one can capitalize on the residual vision present. Hopefully, an ophthalmologist can be utilized in consultation to assure the other disciplines that no further surgical procedure is warranted and that the proper postoperative aphakic lens has been prescribed.

A gross evaluation of the present hearing status of the child can be clinically presumed; however, proper audiological and otological evaluation is certainly in order.

Of major concern is the neuromuscular status of the child as to the safety in his ambulation and analysis of his gait. Following this, recommendation may be made for physical therapy.

High interest material including light attraction will allow the pediatrician to assess the function of the upper extremeties and dexterity in hand use. Fully realizing that activities of daily living independence is a primary goal and assessment of these abilities can be done during the examination.

Responses to sound, utilizing gestures, chatting with the parent in a detailed history of how they communicate with the child and how the child communicates with them is indeed important and leaves the pediatrician with an overall assessment of the present status of their communication ability. How does the child express his wants and desires to the parents, if he does. Certainly, we have seen many children that are and remain self-stimulatory pseudo-autistic, not seeking out their environment and functioning on a low sensorimotor level of development. Of course, the needs and programs for this type of child must be geared to a lower level.

Since the majority of these youngsters are quite small, falling below the 10th and even third percentile for their chronological age, their general nutritional status becomes important. For that reason,

basic laboratory tests may reveal an underlying iron deficiency anemia or even silent urinary tract infection which requires further investigation. Indicated X-rays may assist in evaluating the present cardiopulmonary system. We utilize electro-encephalography to uncover silent seizure activities, such as petit mal epilepsy, and, on various occasions, see slow wave abnormalities compatible with a rubella encephalopathy.

I find that it is extremely important to describe this particular deaf-blind child in a way that will be useful to teachers so that they may be aware of the abilities of the youngster and not merely see labels such as postoperative congenital heart lesion with ligation of a patent ductus arteriosus or generalized hypotonia or microcephaly, etc. Medical diagnoses and terminology does little to assist the people who are actually working with this child. So we feel it is necessary to describe what the child can do, what he can see, what he can hear, and whether he ambulates safely within a structured environment.

Utilizing a functional approach to the evaluation of the child seems mandatory if it is at all going to be useful to his ongoing treatment program.

THE EAR SPECIALIST'S ROLE

IN

MANAGEMENT OF THE DEAF-BLIND CHILD

LaVonne Bergstrom, M.D.

It is administratively convenient, but medically inaccurate, to consider "deaf-blind children" as comprising an entity. Varying degrees and times of onset exist for both handicaps. 1) The child may be congenitally deaf and lose his vision later. 2) The child may be congenitally blind and lose his hearing later. 3) Both handicaps may be of later, but not necessarily simultaneous, onset. 4) Both handicaps may be present congenitally but to a partial degree. 5) Each handicap may be progressive but one or both may remain partial. 6) The hearing loss may be sudden, rather than progressive. 7) Genetically-determined degenerations of the eye and ear may not become manifest until adult life. 8) The congenitally totally blind and totally deaf infant is rare. One of the first bits of expertise that the otolaryngologist (ear, nose and throat specialist) or the otologist (ear specialist) can bring to the multidisciplinary group dealing with the hearing-and-visually-handicapped population is that total deafness occurs in only about 1% of profoundly congenitally deaf children and as a result of meningitis in no more than 10% of all prelingually deafened children. Total congenital absence of response to sound apparently occurs only in aplasia or failure of development of the inner ear, a rare anomaly not known to be associated with visual loss. In nearly all other "deaf" children some residual hearing is present which is potentially useful if the hearing loss is detected early. "Deaf-mutism" is an archaic term, since all deaf persons have normal vocal and articulatory structures. Most of them can acquire at least some speech, although pronunciation and vocal quality may not be good.

Congenital hearing losses are of three types: 1) sensori-neural (older terms: perceptive or nerve deafness); 2) conductive (that affecting the outer or middle ear sound transmitting apparatus only); and 3) mixed sensori-neural and conductive hearing losses. Pure conductive hearing losses may be associated with delayed speech, poor acquisition of language, articulation errors and impaired performance in school. These manifestations would tend to be more severe in the severely visually handicapped youngster who cannot read lips or get other visual clues important in total hearing performance.

The audiometric pattern in sensori-neural hearing losses is important in assessing function, habilitation and rehabilitation.

The child with a moderately severe, but flat, loss may function better with amplification from a hearing aid than the child who has normal hearing in the lower frequencies but a sharp drop off in the middle and high frequencies. Furthermore, the first child may benefit from having his hearing loss detected early, while the second child, especially if he also suffers from a significant visual impairment, may sustain nearly irreversible psychological and educational misdiagnosis before his true handicap is discovered.

We see, then, that a simplistic approach to "deaf-blind" children is not tenable. The concept becomes more complex when it is realized that a significant proportion of these already doubly handicapped children suffer from disorders of other body systems. Table I summarizes the findings in a group of deaf-blind children at the University of Colorado Medical Center. Most of these children were seen in the Birth Defects Center; the rest were about equally divided between the otolaryngology clinic and the John F. Kennedy Center. It will be noted that a large proportion of these children are victims of intrauterine rubella, well-known for its devastating effects on multiple organ systems. At any rate, it is highly likely that the "deaf-blind child" will have other problems.

The otologist can function as an individual contributing to the diagnosis and evaluation of such children. Parents of a congenitally deaf child may seek his aid first, and he should be prompt to not only examine the child, but to take a careful family, prenatal and perinatal history and to obtain immediate, competent audiological testing for the child. If anything in his history or examination of the child suggests the additional possibility of congenital or later-onset visual problems he should encourage early multidisciplinary evaluation of the child and the family.

At this point the otologist's role as an individual practitioner ends. He may continue to function as a member of a team devoted to the deaf-blind child if he is affiliated with an appropriate center. However, in my opinion, the deaf-blind child or the child who shows the stigmata of a genetic disease in which these handicaps will ultimately occur, should not be at the mercy of fragmented evaluation and planning. The appropriate role for the otologist is that of functioning as a member of a team of specialists in this field. Ideally a center for the diagnosis and evaluation of these children should be part of or closely affiliated with a medical school or teaching and research center. There are several reasons for this. A medical school has within its walls, easily available, consultants in nearly every field pertinent to the evaluation of the "deaf-blind" child. It serves as a prime reservoir of and relentless searcher for new knowledge. In the field of congenital and genetically-determined hearing loss there are in the United States only a handful of persons fully familiar with the embryology, clinical manifestations, disturbed physiology and temporal bone pathology of this specialized area of otolaryngology. Virtually all of these persons are affiliated with medical schools. Regional temporal bone banks, set up to study the pathology of deafness, are located in medical schools and staffed by otolaryngologists and otologists who have made this a subject of special interest. Providing

clinical service to hearing and visually handicapped individuals is Praiseworthy and important. However, it is limited in its effectiveness if not combined with an attempt to study the total patient and, indeed, if the therapy proposed is not evaluated in a systematic and scholarly way. The medical school can provide at least one other service not available in most smaller communities. This is genetic counseling for the families and the victims of hereditary eye-ear disorders. Certain tools of the geneticist, e.g., amniocentesis for intrauterine diagnosis, are pertinent to our discussion. One genetic disorder, Refsum's disease, in which later onset, progressive deafness and blindness occur, can now be diagnosed in the unborn child by this method. These techniques and the laboratories for the specialized tests are not widely available.

The medical school can be a pioneer in developing and evaluating new methods of early diagnosis. In our institution one method of neonatal hearing screening has been developed, a method we feel is highly successful. We have also developed a High Risk Register for the early detection of the child who is at risk for congenital or genetically-determined later-onset hearing loss. This Register should be capable of detecting the "deaf-blind" population also. With the aid of the Register we have lowered the average age of diagnosis of congenital profound sensori-neural hearing loss from 20 months of age to 6 months of age. We are continuing to develop and evaluate this tool. (see Table II)

What is the role of the otologist or otolaryngologist in the multi-disciplinary center for the deaf-blind child? He will do a careful ear, nose, throat and head and neck examination of the child, and he will add his observations of cranial nerve function to those of the pediatrician, ophthalmologist and neurologist. Examination of the ears with the operating microscope is very helpful and, indeed, mandatory in infants in whom evaluation of ear drum mobility is inaccurate by other methods. With the use of the microscope he can carefully clean ear canals, even in young, active children, so that a complete examination can be done and so that the ear canals may be clean, allowing better hearing aid function. Deaf children who are also blind, or at any rate too young to fully understand what is being done to them, are less likely to be traumatized physically and psychically if such routine ear care is done gently and skillfully. The microscope makes this much easier.

Such children are just as prone to acute otitis media, secretory otitis media and recurrent tonsil and adenoid disease as normal children. However, the temporary or chronic effects such disorders may have on the functioning of a "deaf-blind" child are probably more serious than they are on a normal child. Also the deaf child is less apt to complain of a further, although small, decrement in this hearing. Therefore, the otolaryngologist should carefully re-examine the tympanic membranes and nose and throat on each visit and treat appropriately. Children with hearing aids may suddenly refuse to wear them, and it may be because the ear mold is irritating the canal or because the ear has grown and the mold has become too loose. This can cause irritating squealing due to feedback which can be uncomfortable to

those patients who hav sufficient hearing to hear the feedback. Both the audiologist and the otolaryngologist should check the ear molds at each visit.

Vestibular function or equilibrium is often impaired in "deaf-blind" children. This dysfunction is often asymptomatic if it has been present from birth. In other instances it may appear later, and a documentation of baseline function is very important. The presence of peripheral vestibular function may be established by turning tests, as in the Barany chair, or by torsion or parallel swing tests. These examinations do not assess the intactness of each end-organ separately, but are often the only tests feasible in infants and young children. Electronystagmography may be used to record the nystagmus induced by these stimuli. Children over the age of 5 or 6 may have caloric testing done, which will give a separate evaluation of each inner ear vestibular response, and again electronystagmography may be used to record the response, as well as to record any spontaneous nystagmus present. Blind children often have ocular nystagmus, which may make the gross assessment of superimposed vestibular nystagmus somewhat difficult, but the electronsystagmograph is of help in this regard, since the pattern of the nystagmus beat is distinct for each. Evaluation of vestibular function should be done periodically, as signs of beginning deterioration might change vocational counseling for the older child or adolescent. Vestibular testing is still somewhat crude, even with the more sophisticated instrumentation now available. Individuals who can interpret the tests and combine this knowledge with their clinical assessment of inner ear balance function in children are generally not available outside of medical schools.

Occasionally congenital conductive hearing losses or apparent total absence of hearing make it desirable to have a "look" at the ear. Special x-ray studies, using the technique of petrous pyramid polytomography, can demonstrate nearly all bony abnormalities of the inner ear. The otologist, in consultation with this colleagues, can decide which child would benefit from having these special studies done. He can also assist in the interpretation of these films, although most medical school x-ray departments would have radiologists specially trained in this area. If the child lacks an inner ear the otologist can explain this to other members of the team, and the child's training can be re-directed.

The x-rays and another specialized test, impedance audiometry, may indicate that the child may be a candidate for specialized otologic surgery, either myringotomies and the placement of tubes for a chronic middle ear effusion, or reconstructive surgery for middle ear anomalies which interfere with the proper transmission of sound. The otologist or otolaryngologist trained in modern oto-surgical techniques can offer this service to the "deaf-blind" child.

Hearing conversation should be part of the management of these children. This includes 1) prompt care of any ear complaint; 2) regular otologic and audiologic evaluation; 3) avoidance of trauma to the ears such as might be caused by self-cleaning of cerumen from

the canals; 4) avoidance of ototoxic drugs, where possible, since an already defective ear may be even more sensitive to the effects of ototoxic medications than a normal ear. Also some ototoxic medications affect primarily the balance end-organ of the inner ear, rather than the hearing. Loss of peripheral vestibular function may be a disaster in an already blind person; 5) avoidance of vocation or avocational acoustic trauma (excessive industrial noise, rock and roll music are examples). These precautions are all aimed at minimizing exogenous causes of hearing loss and preserving usable hearing for as long as possible.

The otologist may add his knowledge of prognosis regarding the hearing to that garnered by other members of the team. He can participate in family studies of hearing function which may be necessary to determine whether or not a given child has a genetic eye-ear disorder.

It is apparent that neither the otolaryngologist nor the ophthalmologist nor the two together can assume the burden of evaluation and continuing care of the deaf-blind child...or the deaf child who becomes blind...or the blind child who becomes deaf...or the apparently normal child doomed to become both deaf and blind. The ear specialist assumes his rightful place in a team which ideally also includes an ophthalmologist, pediatrician, geneticist, neurologist, audiologist, clinical psychologist, social worker, speech therapist, physical therapist, teacher and vocational counselor.

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TABLE I

Eye, Ear and Other Abnormalities in

Deaf-Blind Children

University of Colorado Medical Center

Pt. No.	Eye Manifestations	Type and Degree of Hearing Loss	Associated Defects	Etiology
1.	Cataracts	S-N* - Severe	Congen. heart disease	Rubella
2.	Cataracts	S-N - Severe	Patent ductus	Rubella
3.	Optic atrophy	S-N - Unilat., mild, mid-freq.	Mental retardation, seizures	Rubella
4.	Cataracts	S-N - Mod. severe	? mental retardation	Rubella
5.	Cataracts	S-N - Severe	Mental retardadation, growth retardation, congen. heart disease	Rubella
6.	Retinal & disc colobomata	S-N - Profound	Congen. heart dis., mental retardation	Rubella
7.	Decr. vis. acuity, strabismus	Conductive	Mental retardation, congen. heart dis.	Familial
8.	Severe myopia	S-N - Mild	Abnormal facies, mental retardation	Familial
9.	Cataracts	Central auditory imperception	-----	Rubella
10.	Cataracts, microphthalmia	S-N - N.R. R. ear Severe - L. ear	Mental retardation, microcephaly, congen. heart dis.	Rubella

Table I (continued)

Pt. No.	Eye Manifestations	Type and Degree of Hearing Loss	Associated Defects	Etiology
11.	Myopia, glaucoma, cataracts	S-N - Mild	------	Familial
12.	Total retinal detachment, high myopia	S-N - Mild	------	Familial
13.	Choroid colobomata	Conductive	Hypoplasia of shoulder girdle, choanal atresia, ? mental retardation	?
14.	Cataract, Unilat., high myopia in other eye	S-N - Severe	Patent ductus, mental retardation	Rubella
15.	Retinitis pigmentosa	S-N - Profound	? vestibular involvement	Usher's
16.	Retinitis pigmentosa	S-N - Profound	------	Usher's
17.	Cataracts	S-N - Severe to profound - progressive	Mental retardation, microcephaly, poor vestibular function	Rubella
18.	Retrolental fibroplasia	S-N - Profound	------	?
19.	Congen. glaucoma	S-N - Profound	Dysgammaglobulinemia	Rubella Histiocytosis-X

* S-N = Sensori-neural

TABLE II

Syndromes in Which Significant Visual and Hearing Loss May Be Associated

University of Colorado Medical Center

Syndrome	Onset and Degree of Visual Defect	Onset, Type and Degree of Hearing Defect	Etiology
Alport's	Congenital Anterior lenticonus Spherophakia Cataracts Myopia	Progressive - S-N	Dominant (genetic)
Alstrom's	Progressive Retinal degen. Diabetes mellitus	Progressive - S-N	Recessive (genetic)
Amalric's	Congenital Macular dystrophy	Congenital - S-N	Recessive
Arthro-ophthalmopathy	Progressive Retinal detachment	? congenital mild S-N	Recessive
Bony Skull Disorders			
Apert's	Progressive Optic atrophy	Congenital conductive	Dominant
Craniometa-metaphyseal dysplasia	Progressive Optic atrophy	Progressive - S-N Conductive	Dominant
Crouzon's	Progressive Optic atrophy	Congenital Conductive Progressive - S-N	Dominant

Table II (continued)

Syndrome	Onset and Degree of Visual Defect	Onset, Type and Degree of Hearing Defect	Etiology
Osteopetrosis	Progressive Optic atrophy	Progressive S-N or Conductive	Recessive
Cockayne's	Progressive Retinal atrophy	Progressive - S-N	Recessive
Cryptophthalmos	Congenital Buried globes	Congenital Conductive	Recessive
Ectodermal dysplasias	Congenital Cataracts Fluid vitreous	Congenital or Progressive S-N	Recessive or Dominant
Eldridge's	Congenital High myopia	Congenital - S-N	Recessive
Fehr's	Progressive Corneal degeneration	Progressive S-N	Recessive
Flynn-Aird	Progressive Myopia	Progressive - S-N	Dominant
Goldenhar's	Congenital Colobomata Rare:Anophthalmia	Congenital Conductive	? Recessive
Hallgren's	Progressive Retinitis pigmentosa	Progressive - S-N	Recessive
Laurence-Moon-Biedl-Bardet	Progressive Retinitis pigmentosa	Congenital - S-N	Recessive
Norrie's	Congenital Pseudotumor of retina	Progressive - S-N	X-linked (genetic)
Oculomandibulodyscephaly	Congenital Cataract	Congenital Conductive	Recessive

Table II (continued)

Syndrome	Onset and Degree of Visual Defect	Onset, Type and Degree of Hearing Defect	Etiology
Ophthalmoplegias Duane's Klippel-Feil Moebius Abducens P.	Congenital	Progressive S-N or Congenital Conductive	Dominant or Recessive
Optico-cochleodentate degen.	Progressive	Progressive - S-N	Recessive
Refsum's	Progressive Night blindness Retinitis pigmentosa	Progressive or sudden S-N	Recessive
Roaf's	Congenital Retinal detachment	Congenital - S-N	?
Rubella	Congenital Cataracts Retinitis	Congenital ± Progressive S-N, occasionally conductive	Rubella
Testicular insufficiency, metabolic abnormalities	Progressive Cataract, vitreous opacities, attenuated retinal vessels	Progressive - S-N	? Recessive
Usher's	Progressive Retinitis pigmentosa	Congenital - S-N	Recessive

THE ROLE OF THE OPHTHALMOLOGIST IN THE DIAGNOSIS AND EVALUATION OF DEAF-BLIND CHILDREN

Max Kaplan, M.D.

Severe degrees of impairment of vision and hearing deprive the affected individual of the two most important and effective modalities of sensory input. Either of these disabilities alone provides serious handicaps to the physical, intellectual, and psychological growth and stability of the one affected; the combination of the two in the same individual results in disability greater than the sum of the two.

The infant and child growing up in a world that can be seen only poorly, if at all, and can be heard only poorly, if at all, is in a world far different from that in which the child with good vision and good hearing grows up. The factors which will determine how different that world will be for the deaf-blind child are numerous, and for those working in the areas of responsibility for helping those so afflicted, it is essential to recognize these factors. If this world is to be made more receptive for such a child--more helpful, more tolerable, more understandable--and if the child and his family are to be guided toward a happier and more satisfying life in that world, then all of the disciplines in the medical, social, and educational sciences must accept their respective roles and responsibilities.

The role of the ophthalmologist is a multi-faceted one. He must attempt to establish the diagnosis of the cause and pathogenesis of the visual problems, and the quantitative assessment of the visual capabilities of the child, actual and potential. He must develop a treatment plan that will provide maximum conservation of whatever vision is present and at the same time a plan for maximum improvement in vision, whenever improvement is possible, utilizing his complete armamentarium of medical and surgical methods and techniques. He must recognize that time is important, and that the younger the age at which the visual disability is recognized, diagnosed, and treated, the better is the outlook for attaining an optimum result, not only visually, but also developmentally, emotionally, and educationally. He must coordinate his investigations and planning with the pediatrician, the otologist, the neurologist, the psychologist, the psychiatrist, the genetic counselor, the social worker, the speech pathologist and audiologist, the teachers and special educators. He must recognize the importance of his role in assisting

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the parents and family of the child to understand and accept their roles in meeting and managing their complex problem. He must appreciate that the intellectual growth and the emotional health of the child will be directly dependent upon the emotional stability of the parents and family, and he must help guide and strengthen them by his patient and kind understanding, his willingness to provide explanations of the diagnostic and therapeutic procedures, and the prognostic problems at hand. All conversations with the patient and family should be as optimistic and hopeful in outlook as possible and still be consistent with the known facts.

The ophthalmologist's approach to the deaf-blind child will vary with the circumstances existing and the information available at the time the child is seen. If the infant is already known to be deaf when brought to the ophthalmologist, this knowledge will tend to direct his diagnostic approach toward those syndromes in which there is a higher than random incidence of hearing defects with visual and ocular defects. Conversely, if the child is not known to have impaired hearing and the ophthalmological examination discloses findings that are known to be associated with hearing defects more frequently than on a chance basis, then the ophthalmologist should initiate, along with the family physician or pediatrician, referral to the otologist for investigation of the child's auditory status.

Thus, as an example, the most frequent cause of combined severe visual and hearing impairment in infants and children today is the Rubella Syndrome. Once this diagnosis is established, by whatever routes and criteria, it is mandatory that both the ophthalmologic and otologic status of that child be investigated. Furthermore, it must be recognized by the ophthalmologist that in many of the syndromes in which vision and hearing are impaired, other organ systems, in addition to the eye and ear, may frequently manifest pathologic findings. So he must be guided also by the knowledge that mental retardation may coexist in these children, or renal disorders, or abnormalities of other organ systems.

The causes of the hearing and visual defects in the great majority of deaf-blind children are congenital or hereditary. The defects may be present at birth, even though they may not be diagnosed or even suspected or recognized until sometime after birth. Some of the defects may not be overtly present at birth and may not begin to become manifest until adolescence or later. In these the "seed" is present, so to speak, planted there by genetic or pre-natal environmental influences, but the "seed" does not grow into its fruit of defectiveness until the child is older, or indeed in some instances, until he reaches adulthood. Furthermore, the defects in two or more organ systems are not necessarily parallel, either in severity or in time. Thus, quantitatively, a very mild hearing impairment may be associated with a severe visual defect, or the reverse may be true. Temporally, the hearing defect may appear at birth but the visual defect may not appear until much later, or vice

versa. These quantitative and temporal variables must be kept in mind in the course of the diagnostic, therapeutic, and educational planning for these children.

The implication of these variations has been emphasized recently by Vernon (1) in a discussion of Usher's Syndrome, a genetic condition resulting in the double handicap of congenital deafness and progressive blindness from retinitis pigmentosa. It is a rare autosomal-recessive inherited condition which generally does not manifest itself until relatively late in life, and is frequently associated with psychosis, mental retardation, and other neuro-physiological pathology. In most early studies of Usher's Syndrome the diagnosis of retinal degeneration was generally made by questionnaires, or in some cases, by ophthalmoscopic examination, visual field tests, or both. These procedures are inadequate for the detection of many cases of retinitis pigmentosa, especially in children, cases which can now be more accurately diagnosed by the use of electroretinography, evoked cortical visual responses, and other newer techniques. "Thus", says Vernon, "it is probable that an appreciable percentage of cases (of Usher's Syndrome) in younger children have been overlooked (in the older studies), meaning that stated prevalences (of the disease) are likely to be underestimates." "In fact", he adds, "many of the specialists who are most likely to see deaf or blind children are not even aware of the existence of Usher's Syndrome. The auditory and visual problems of the disease are often thought to be separate and unrelated. Conventional diagnostic procedures have depended on ophthalmoscopic and visual field examinations only, with the result that the diagnosis (of retinitis pigmentosa) is usually delayed until the patient is a teenager or out of school. By then, maximally effective preventive genetic counseling of the parents is often too late, as they may have had additional children!"

The significance of this is not only as it applies to the individual and the family involved, but on a broader scale in a program of prevention of Usher's Syndrome which is both feasible and potentially effective. Thus, the only population which has the disease, Vernon points out, is in the group of the congenitally deaf. From this group it should be relatively easy to provide these few children the ophthalmological investigation required for early detection, detection which also leads to the identification of carriers and to the genetic counseling required to avert further spread of the disease.

Still another area of relevance and importance for the ophthalmologist and otologist is the recognition that embryologically there are definite similarities in the origin and development of various elements of the eye and the internal ear. The awareness of these embryological similarities not only raises the physician's index of suspicion about abnormalities in one organ system when congenital or hereditary defects are found in the other, but it also may provide diagnostic help for the physician as to the cause, pathogenesis, time during

embryogenesis when a defect may have been produced, and possible relationships to defects in other organ systems.

These embryological similarities (2), briefly described, include the following:

(1) The neurosensory structure in both the eye and ear derive from the ectoderm by an analogous process; their fibrous and vascular envelopes result, in both organs, from thickening and organization of mesenchyma surrounding the neurosensory structures;

(2) Curves of embryonic and fetal growth of the eye and internal ear are similar; the first phase in their formation takes place during the latter part of the first month and the early part of the 2nd month of intrauterine life;

(3) The ganglionic crest is significant in development of the internal ear and in the pigmentation of the uveal tract of the eye.

Although there is no morphologic resemblance between the ocular globe and the internal ear, anatomic organization of the two structures presents numerous similarities. The organ of Corti, giving rise to filaments of the cochlear nerve, is the anatomic and physiologic equivalent of the retinal neuro-epithelium. Around it, as around the retina, are structures assuring its protection and its nutrition.

This comparable structural organization supports parallel biologic processes, with a marked analogy between the endolymph and aqueous humor. The endolymph is a product of secretion elaborated by the stria vascularis, whose embrologic origin and anatomic structure are very similar to those of the ciliary body. Just as there exists a selective blood-ophthalmic barrier, so is there an active blood-labyrinthine barrier separating the blood mass from the internal ear.

We see an example of the associated involvement of the ear and of the uveal tract of the eye in the hereditary syndrome of Waardenburg. This syndrome is transmitted by an irregular autosomal dominance mode, with variable penetration and expression for its different elements. In its complete form, Waardenburg's Syndrome combines anomalies of the internal angle of the eyelids and base of the nose, partial albinism, in which the uveal tract participates, and inner-ear (labyrinthine) deafness.

Acquired lesions of the uveal tract of the eye, including the iris, ciliary body, and choroid, are usually due to infections--bacterial, parasitic, or viral. Syphilis, hereditary or acquired, may affect the uveal tract and the ear, separately, simultaneously, or successively, at any stage in its course. The recent marked increase in the incidence of acquired syphilis provides cause for the physician to keep in mind that combined impairment of vision and hearing in the

infant and young child can be due to congenital syphilitic infection.

To discuss, or even list, all of the diseases and syndromes in which visual impairment may be associated with auditory impairment is beyond the scope of this presentation. To say that such a list would be long (and still growing) would probably be an understatement. However, in pointing up the role of the ophthalmologist in the medical management of deaf-blind children, it should be of some value to take a look at a partial list, at least, of some of the diseases and syndromes in which the association of hearing and visual impairment can occur, some frequently and some only occasionally. Among the benefits of looking at such lists is the very challenging, and almost awesome one, of indicating to the ophthalmologist the large number of neonatal, pediatric, neurologic, congenital, and acquired diseases with which he should become familiar if he is to be adequately informed in his task of participating in the care of these children.

The first list is of those diseases and syndromes with ophthalmologic abnormalities in which deafness is frequently associated; the second contains those in which deafness is occasionally associated. Both lists have been modified from D.W. Smith's publication, Recognizable Patterns of Human Malformations (3).

Table I

Diseases and Syndromes with Ophthalmologic Abnormalities
Frequently Associated with Deafness

Rubella Syndrome
Cockayne's Syndrome
Goldenhar's Syndrome
Hurler's Syndrome (Mucopolysacharidosis I)
Hunter's Syndrome (Mucopolysacharidosis II)
Morquio's Syndrome (Mucopolysacharidosis IV)
Waardenburg's Syndrome
Treacher-Collins Syndrome (1st Arch)
13 Trisomy Syndrome (D Trisomy)
Long Arm 18 Deletion Syndrome
Stickler's Syndrome (Progressive Arthro-Ophthalmopathy)
Ectodermal Dysplasia, Marshall's Type
Ring Chromosome 18 Syndrome
Congenital Syphilis

Table II

Diseases and Syndromes with Ophthalmologic Abnormalities
Occasionally Associated with Deafness

Cruzon's Syndrome
Fanconi's Syndrome
Laurence-Moon-Biedl-Bardet Syndrome
Cleidocranial Dysostosis Syndrome
Osteogenesis Imperfecta
Oculo-dento-digital Syndrome
Progeria
Congenital Toxoplasmosis
Severe Osteopetrosis (Albers-Schönberg)
Retrolental Fibroplasia
Congenital Toxoplasmosis
Kernicterus
Juvenile Diabetes Mellitus with Optic Atrophy
Choroido-retinal degenerations (Leber's congenital amaurosis)
Turner-like Syndrome (Male Turner's Syndrome; Noonan's Syndrome)
Scheie's Syndrome (Mucopolysaccharidosis V)
XO Syndrome (Turner)
Robin Syndrome (Pierre Robin)
Weill-Marchesanni Syndrome
Moebius Syndrome (Congenital Facial Diplegia)
Hallerman-Streiff Syndrome (Oculomandibular Dyscephaly)
Pseudohypoparathyroidism
Oculo-Cerebro-Renal Syndrome (Lowe's)
Pseudoglioma (Norrie's Disease)
Refsum's Syndrome (Heredopathia atactica polyneuritiformis)

The ophthalmologist is repeatedly faced with this reality that many of these children have not only abnormalities of the eyes and the ears, but abnormalities of other organ systems as well. The ophthalmologic problems must always be evaluated in the light of the other problems that exist. This varies, of course, with the disease or the syndrome, and to illustrate this multiplicity of organ system involvement, I chose one of the most notorious of them all--the Chronic Rubella Syndrome. I reviewed nine cases of this syndrome from our Birth Defects Low Vision Clinic at the University of Colorado Medical Center and have just listed briefly the diagnoses shown in their records. (See Table III, next page)

Table III

Organ System Involvement in Chronic Rubella Syndrome

Pt.	BD.	Eyes, Vision, etc.	Ears, Hearing, etc.	CNS	Other
D.M.	12/12/64	Congenital Glaucoma (Surgery)	Severe neuro-sensori loss		Histiocytosis X (Letterer-Siewe Disease), Dysgamma-globulinemia, Subaortic Stenosis
W.R.	2/2/65	Bilateral Cataracts (Surgery)	Prob. neuro-sensori loss; No speech	Mental retardation	Behavior problems; Patent Ductus Arteriosus
O.D.	11/21/67	Bilateral Cataracts (Surgery)	Severe neuro-sensori loss	Large head with frontal bossing	Patent Ductus Arteriosus, probable ventricular septal defect, delayed development
S.C.	12/15/64	Microophthal-mia, L.E. Bilateral Cataracts (Surgery R.E.) Photocoag. R. Iris Discussion of membrane R.E. Surgery L. E. Vitreous loss Capsulotomy & Sphincterotomy Sector Iridectomy L.E.	Auditory integration problem (central); No speech	Mental retardation, severe	
M.R.	12/16/65	Bilateral Cataracts Microophthalmia (Surgery	Bilateral neurosensori loss, severe; No speech	Mental retardation, severe	Patent Ductus Arteriosus (Surgery), Taps jaw with hand to make teeth click, Stands on head for long periods
G.P.	11/24/64	Bilateral large Colobomas of choroid and optic nerve; Salt-Pepper fundus with much pigment disorganization	Bilateral neurosensori hearing loss, severe	Mental retardation, severe Microcephaly Facial Palsy	Patent Ductus Arteriosus (Surgery), Possible mild aortic stenosis, Submucus cleft palate

Table III (contd)

Pt.	BD.	Eyes, Vision, etc.	Ears, Hearing, etc.	CNS	Other
K.S.	5/13/65	Colobomata, extensive, of chorcid, optic nerves, macular areas Strabismus Microcornea L.E.	Conductive hearing loss, severe; Delayed speech	?Mental retardation (borderline)	Choanal atresia, Facial asymmetry, Hypoplasia of shoulder girdle muscles
B.S.	11/18/59	Bilateral Cataracts, R. microophthalmia R. esotropia Diffuse salt-pepper disturbance of fundus	Neurosensori hearing loss, severe; No speech (Chronic Serous Otitis; myringo-tomies with poly-ethylene tubes)	Microcephaly	Deviant behavior, with psycho-therapy
C.M.	4/28/65	Bilateral Cataracts Surgery with cataract membranes Alternating esotropia Severe visual impairment Pendular nystagmus	Neurosensori hearing loss, severe	?Mental retardation	Emotionally disturbed

The ophthalmologist can sometimes make real contributions to the total etiologic and diagnostic evaluation of a given patient that is beyond the actual ophthalmologic diagnosis. When the findings of the other physicians may not point conclusively to a definite and specific diagnosis, the ophthalmologist may be able to provide the needed confirmatory information. Thus, the finding of the typical pigmentary retinopathy, though not pathognomic of congenital rubella, is so characteristic that it may well provide the necessary added piece of evidence to establish that diagnosis. Similarly, a typical chorioretinitic lesion localized in the macular area may be very helpful in establishing a diagnosis of congenital toxoplasmosis.

Likewise, the ophthalmologist's findings may help to establish the genetic nature of a disorder in an infant with one or more congenital abnormalities. Francois (4) has emphasized that "in cases of colobomatous lesions of the eyeball, and particularly in cases of coloboma of the iris or uvea, coloboma at the entrance of the optic nerve, microophthalmia, or anophthalmia, one should suspect immediately the presence of a genetic factor."

"The occurrence of similar colobomatous lesions in several members of the same sibship or of the same family, most probably points toward Mendelian heredity. In these cases, equivalent and minor manifestations in other members of the family should be looked for."

"When the colobomatous lesion occurs sporadically and especially when it is associated with general malformations, one should look for chromosomal aberration and evaluate the case cytogenetically."

In addition to colobomatous lesions, many other specific types of ocular malformations have been found to be associated with chromosomal aberrations. These include choroido-retinal degenerations, high myopia, congenital cataract, pseudoglioma of various types, optic atrophy, palpebral anomalies, and others. These may frequently be associated with abnormalities of other organ systems and they may comprise one component in some of the syndromes listed above in which eye abnormalities are associated with deafness.

Thus, in the group of choroido-retinal degenerations, including the tapeto-retinal degeneration known as Leber's congenital amaurosis, there may be variants of the syndromes, with associated clinical features such as renal abnormalities and concomitant neurological abnormalities, at times including deafness. In this group o diseases, it appears that autosomal recessive forms give rise to more severe lesions of earlier onset than autosomal dominant forms, and therefore the former are almost exclusively represented among children with severe degrees of visual impairment.

Characteristically, Leber's congenital amaurosis is marked by visual failure from earliest infancy. At first no retinal lesion may be visible

component of his program.

Be cautious with the diagnosis of hyperactivity. This label means so much to so many, and so little to so few. This type of behavior needs to be viewed critically. The question I try to ask is: Is this child gathering information, and can I help him control the information getting process in order that he receive a more organized picture of his environment?

Another pitfall that might be warned against is the forgetting of language training when oral language looks like an impossibility. Remember that language is a system of communication through symbols. Look at all the alternatives left when oral language is no longer an alternative.

Techniques and Strategies for Developing Speech and Language in the Deaf-Blind

Within the population of deaf-blind you will find a great variety of hearing problems: from the child who hears nothing at all, to the child who may hear sound but finds it difficult to make sense of the sound, to attend to sound or to remember the sound. Within the same population these same children will have a variety of visual problems: from the child who sees nothing at all, to the child who has trouble making sense of that which he does see well. Statistically I would imagine the combination of the two types of sensory impairment could go on indefinitely.

In the child who exhibits the rubella syndrome there exists the possibility of involvement in many other modalities - Cerebral Palsy or motor involvement of varying degrees; Neurological involvement which may exhibit itself behaviorally in distractability; hyperactivity; perseverative behavior; and attention span difficulties, etc. The child may or may not have cardiac problems which may contribute to his susceptibility to disease which may, in turn, affect his experiential level. The sick child does spend much of his time in bed and gains very little experience there. These children seem to exhibit more than the average amount of eating problems and toilet training problems.

All of these possibilities exist and all of them are relevant to the child's total development as well as to his language development.

The degree and the type of hearing loss the child has certainly makes a difference in what kind of communication system the child will use. The degree and type of visual impairment in combination with his hearing loss is going to influence the type of communication system that the child uses.

One of the techniques we use for the development of oral language or speech is the Vibration Method - Tadoma Method. This is the method where the child places his thumb on or near the speaker's lips and then places his fingers on the cheek of the speaker. The

tactile information supplements the missing visual cues and may fill in the gaps for incomplete auditory cues. This is a multisensory approach. Of course, with some of the children you see this technique may not be necessary because of the limited impairment to the auditory and visual senses. Even with the children in our program who have quite functional close-up vision, this technique seems to give them added information about speech sounds and makes a difference in their production of the same speech sound.

The questions will be aksed, "Where do you begin?" This can only be answered by you and the child. You begin where he is, and maybe even below the level where he is functioning.

Another technique that can be used to help the child develop a language system is the manual method of communication. This is a method in which movements of the hands and fingers are used as symbols for ideas. This method follows the same developmental steps as does oral language. The child sees and/or feels the movement before he uses the movement. There is much contact with the direct experience before the symbol is introduced. The experience and the symbol are then connected through much repetition.

Another technique that we have found useful, especially with the more multiply involved children in our program, is a signal type of language system. This is a primitive language system and is usually used in relation to physiological needs. For example, when the child has to go to the bathroom he tugs on his diaper. Again in this type of system, the direct experience precedes the introduction of the signal. The adult first presents the signal to the child. Then he manipulates the child's hands and makes the signal. This would be similar to the listening behavior of the hearing child. This is the receptive phase. Expression of the signal comes later. The adult eventually waits for the signal before the need is met.

I would like to discuss the types of auditory training with which we have been experimenting in our program. It seems that all the children in our program need a great deal of assistance in learning how to listen. The most ideal situations is to have the following: calibrated sound instruments, calibrated sound toys, an amplification system, and an audiologist who will work to develop an audiogram on the child. With this information and an understanding of Jeffers information, you can make the following decisions:

1. Where to begin:
   a. gross sound discrimination
   b. speech sound discrimination
   c. word discrimination
   d. conditioning the child to one sound

2. Which vowels and/or consonants to begin with:
   a. front - mid - back vowels
   b. voiced or voiceless consonants
   c. plosive sounds, fricatives, etc.

3. Which vowels and/or consonants to contrast, which ones will be so similar to the child that they should come much later in the child's auditory training program.

4. What is the immediate goal:
   a. sound awareness
   b. sound discrimination
   c. increased range of frequency response
   d. conditioning the child to a specific sound

In any case, you will have to show the child how to respond to sound. He may drop a block in the box to note his response, he may respond orally or he may gesture, depending upon his level of development.

We feel that the type of information provided by the audiologist curtailed much of our second guessing and made the time the child spent in auditory training more meaningful. It seems to make sense that the sounds used in auditory training should be sounds that are not only usable to the child, but are natural sounds in the environment. At this point I see little value in the teacher attempting to condition the child to pure tones. With frequency information on sound toys and with the formant information on the speech sounds and the child's audiogram, you will be able to estimate the frequency with which you are dealing and its appropriateness for the child.

There are a couple of closing comments I would like to make. I would like to restate the importance of the child having the experience necessary for making language meaningful, regardless of the system used.

It seems to me that most of the children in our population experience upsets or difficulties with interpersonal relations. Language is an interpersonal activity. It seems to me that skill or comfort with interpersonal relations takes precedence to language acquisition. Often times the two can be worked on simultaneously. This needs to be a pleasant and relaxed experience for the child.

Teaching a language system to the deaf-blind child is not simply teaching words, phrases, and sentences. It is a process in which we guided the child in his exploration, we help him make sense of, and organize his environment. We help build concepts in the child through association with the concrete: matching, contrasting, and categorizing the repeated concrete experience. Then we offer less concrete experience with more symbolism, until finally the child has mastered the symbol or the concept. We label these concrete experiences, whether through a signal, gesture, sign, or a spoken or written word, and this is language.

My first hesitation in presenting a written paper is that it may contain information that is interpreted as "ultimate truths". I have had little experience with "ultimate truths", and no experience with these "ultimate truths" and the deaf-blind.

I hope that the observations presented in this paper provides a stimulus

for your critical and creative thinking during your work with the deaf-blind child.

NOTES:

FROM SPEECH AND LANGUAGE GROUP DISCUSSION

Wednesday:

I. General Discussion

A. Questions

1. How can we relate oral language capacity to type and degree of hearing loss?

2. Where can we learn about infant stimulation:

3. Behavior management questions.

4. What is a typical rubella child?

Thursday:

II. Factors Relating to Language Acquisition

A. Oral Language

1. Non-severe hearing loss

2. Experience is showing us that the blind child seems to experience a language delay

3. Children who had encephalitis as fetus are not showing oral language skills

4. Early stimulation from family and family expectations seem to be quite important for language acquisition

5. Emotional climate and stability of family

6. Stage of personal-social development of manipulation is positive but can be extended in home at which time it no longer appears growth producing

7. More involved in self-stimulation

B. General comments

1. Gap between performance in school and in home

2. Need for all day program

C. What do the teachers need

1. College education courses that are grounded in:

a. Child Development

b. Diagnostic Teaching

c. Skills in Evaluation Behavior

d. Task Analyses

2. Professionals

a. Ophthalmologist
b. Physical Therapist
c. Social Work
d. More than Audiogram from Audiologist
e. Pharynglal Studies
f. Psychologist who is flexible and willing to move outside of standardized tests

D. Procedures used in Evaluation

1. Video tape, using schema from Curtis-Donlon
2. Daily dictation
3. Weekly dictation
4. Three-four months summaries
5. Developmental scales

E. Suggestions

1. Expand from deaf-blind to multi-handicapped
2. Teacher is "pivotal" member of evaluation team
3. Long period of diagnostic teaching and observation is necessary in each evaluation of the child
4. Innovative material development--perhaps work through school of engineering in community
5. More research on normative behaviors of the deaf child and the blind child
6. Use the method of communication that the child shows you he can use. Communication is the goal.

THE ROLE OF PHYSICAL AND OCCUPATIONAL THERAPISTS IN ASSESSMENT AND TREATMENT OF DEAF-BLIND CHILDREN

Linda E. Bauer

Traditionally, therapists have rarely been involved in the initial evaluation of children with developmental deviations. After referral to a therapist, the child will be evaluated prior to treatment and periodically thereafter. The therapist may use a developmental schedule, a reflex testing chart, muscle test or other types of assessment. More recently, therapists working in child development centers and high risk pediatric clinics, are called upon to use their expertise in reflex development and motor development to aid in the early diagnosis of central nervous system deficits in children. Therapists working with children showing developmental delays, of necessity, have learned much about child development and generally use a developmental approach in treatment. Therapists, especially those working in an interdisciplinary setting, are better versed in child development, normal and abnormal, the effects of stimulation on growth and development, and the effects of the family on the developing child. Therapists are more likely to be treating not only the child's affected limbs, but aiding in general stimulation and helping the child's family adjust to the defective child.

In the past, therapists have not been active in the treatment of mentally retarded children or deaf-blind children. More recently, they have become involved in treatment of the mentally retarded child and find that muscle tone, level of activity, and general interest in their environment can be enhanced through the stimulation of a progressive developmental activities program.

What is the role of the therapist in assessment of deaf-blind children?

Children born with congenital rubella have a myriad of deficits often including small size and feeding problems, encephalitis and meningitis, central nervous system deficits and mental retardation. These children are often small for gestational age and are therefore subject to respiratory problems, temperature regulation difficulties, infection and weight gain problems, which may produce brain damage. Also, some of these babies are born prematurely and therefore may show the same sequela that the low birth weight infant shows.

Many deaf-blind children may have neuromuscular deficits that are as great a handicap as their vision and hearing deficits. Reflex testing, and gross and fine motor development testing with deaf-blind children are a valuable part of the total evaluation of these multiply-handicapped children. Therapists who handle children daily are in an excellent position to assess muscle tone, equilibrium reactions, and pathological reflexes which are interfering with normal motor functioning. Many of these children are generally hypotonic with poor joint stability in the upper extremities. Many of these children have cerebral palsy, so that they have strong pathological reflexes and increased muscle tone throughout. Some children may show an integrative problem, defensive reactions to various textures and stimuli and often do not explore their environment because of this. Some children may show a motor performance of poor quality.

The implications here for treatment are great. The intelligence and potential of deaf-blind children is often underestimated because of their lack of exploration or interest, and poor motor performance. The child with a neurological deficit can appear to be profoundly retarded because of the inability or fear of movement and therefore lack of exploration and early learning.

What is the role of the therapist in treatment of deaf-blind children?

Treatment for retarded and other "special" children often does not begin until age 6 years, when the school system must accept responsibility for their training. So much time is lost by this system of waiting. Deaf-blind children can attain near-normal motor milestones with a home stimulation program and the support, rather than overprotection, of the child's family.

Early identification and treatment of a defective child whether he be deaf-blind, cerebral palsied or mentally retarded, has long been accepted as an important goal for professionals working with handicapped children. A baby first learns through exploration and play with his own body, then by exploring his environment with his eyes, ears, touch and movement through space. Whatever the restrictions be for the individual child, spasticity, weakness, inability to see or hear, he can be taught to move and explore--first his own body and then his environment.

With the help and understanding from a therapist, a mother can learn to handle her child expertly, so that he does not fear handling or movement. She must also understand that her handicapped child is not fragile and will not break.

The therapist's role then is early general stimulation, help with feeding and drooling problems when indicated, inhibition of pathological

reflexes, improvement of movement patterns and later teaching activities of daily living. The teachers of the deaf-blind can be helped to understand a handicapped child's abnormal movement patterns or inability to move, acceptance or non-acceptance of certain textures and stimuli, and/or need for vestibular or proprioceptive stimulation. With greater understanding the of the deaf-blind child's reaction to movement and other stimulation, remedial activities could be incorporated into the daily school routine.

Summary:

Therapists have an important role in the assessment and implementation of a treatment program for deaf-blind children. Deaf-blind children with an additional neuromuscular handicap need an intensive therapy program to realize their potential. It is also extremely important for so-called "normal" deaf-blind children to receive treatment emphasizing stimulation and integration of all their senses. Early identification and early stimulation of these children will better prepare them for formal learning.

PROBLEMS TO THINK ABOUT AND ORGANIZE AT THE MEETING

A. Develop an outline for: Diagnostic Evaluation of Sensory-Motor Functions and Skill Levels

B. Select standard and objective measures to be used in assessment.

C. Outline stimulation and developmental programs to be used in home and school settings for use by parents and teachers.

D. Outline treatment techniques for specific therapy.


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PHYSICAL THERAPY -- OCCUPATIONAL THERAPY

MEETING SUMMARY

The roles of the Physical and Occupational Therapist in an interdisciplinary approach to evaluation and remediation of developmental problems in children were described by Miss Linda E. Bauer, RPT, and Miss Patricia Komich, OTR. Some of the variety of sensory and motor problems encountered with Deaf-Blind children were described, including defensive reactions to tactile input. The therapists' role in early identification and treatment of children with developmental disorders emphasizing teaching the family was stressed. Working with teacher in incorporating remedial activities into the daily school routine was suggested. Suggested problems to consider at the physical therapy-occupational therapy meeting were to develop a common outline for diagnostic evaluation of sensori-motor functions, to select standard and objective measures to be used in assessment in the different programs, and to begin to outline developmental or treatment programs for use in the home, the school, or in therapy.

The group of occupational therapists and physical therapists meeting was small, representation of the various centers in the region incomplete. On exchanging information we learned that the programs represented varied from large multidisciplinary diagnostic and remedial programs which included the Deaf-Blind in a spectrum of developmental disorders to small programs involving only a group of deaf-blind children. The backgrounds of the therapists varied in the level of pediatric or developmental experience or training. The roles of the therapists in the programs varied especially within two important areas -- in early identification in management of infants with developmental problems, and in coordination or integration of the therapies with the educational program.

The therapists dealing with the special problems of the deaf-blind child require a good background in pediatrics or developmental disorders which must often be gained at the post-graduate academic or clinical training level as undergraduate curriculums vary in this area. Acquaintance with the problems, education, and communication training of the deaf-blind child is needed. A need was demonstrated for clinical education workshops and seminars for graduate therapists as well as preparation of materials for publications which could assist undergraduate curriculums.

The possible scope of the role of the physical and occupational therapist in deaf-blind programs was not always familiar to other members of the team. We in the ancillary medical fields are just getting acquainted with working closely with those in education. Let me re-emphasize some of the points made by the therapists this morning about the role of the physical and occupational therapists in programs for the deaf-blind. The developmental assessment has been described as part of the assessment of several disciplines. Physical and occupational therapy assessment goes beyond and under the developmental scale with analysis of why and how the child performs as he does, with exploration of reflexes, of types of muscle tone, as well as structural deviations. Here is an example of a situation in which the the therapist might be able to clarify behavior in developmental testing. A seven month old infant is examined lying on his back. He is offered a toy touching his stomach, and does not bring his hands to it, he does not follow the dangling toy with his eyes or head from one side to the other, and he does not turn his head to the sound of the bell. Does he have a visual or hearing deficit, or is he retarded? The therapist may note that his head is still turned to one side and frequently arching back, his arms in the typical fencing posture of the asymmetric tonic neck reflex. She may test or provoke tone in the distribution of the topic reflexes and realize that he has abnormal patterns of postural tone which interfere with such developmental functions. She may then turn the child to his stomach and position him over a soft chest support and note that here he raises and keeps his head in the midline, turns his head and his eyes to pursue visual or auditory stimuli. He supports on his forearms and has near reach and active grasp and exploration of a toy. In this position his particular interfering tonic reflex patterns are weaker. This difference in response is typical of some cerebral palsied babies but as interaction of normal and abnormal patterns of tone will vary in different children, each child's movement patterns require careful analysis. In helping the delayed or handicapped child progress developmentally, the therapist has available techniques which involve use of sensory input and handling to influence motor output, which can be done with the very young or uncooperative child who cannot cooperate in more traditional types of exercise. In delayed motor development one is dealing not only with "learning" but a disorder of the maturing postural reflex mechanisms -- the automatic basis for what we think of as voluntary movement. Developing a skill such as rolling, one might need to help the child to inhibit interfering abnormal patterns of tone in order to develop the automatic righting mechanisms enabling him to roll voluntarily when he chooses. Motor development does not occur in a simple stair step kind of sequence; there is much overlapping such as: the child develops ability in lying on his stomach to lift his head, support on his arms, and extend his trunk and hips against gravity before he is able to roll to this position, and the development of this postural control is one of the necessary prerequisites for the ability to get into this position. Similarly, the child has ability to sit or to stand before he develops the reactions which bring him to these positions. Development of a

skill may require filling in of important prerequisite patterns or gaps in development, and not just help the practice of skill itself. An example is walking. The child with low tone and poor weight bearing may need to develop anti-gravity control of his trunk and hips before he is ready for walking. If placed on his feet in apparatus such as a walker before he has adequate prerequisite coordination, orthopedic problems may result.

Therapists are increasingly participating in screening programs and clinics for high risk infants. In addition to use of developmental tests such as the Denver Developmental Screening Device, tests such as the Milani-Comparetti Screening Device are being utilized to pick up children showing early deviations in motor development. These relate examination of the developing postural reflex mechanism to functional development. I would like to stress again the importance of early developmental help in all areas not just the hearing problem. In working with any motor handicap early, helping the child utilize and integrate all sensory systems, explore and exploit his environment, we may be able to reduce the child's ultimate handicap. With the infant the concept of "management before diagnosis" has been stressed by Eric Denhoff, T.T.S. Ingram and others, that is while meeting the needs of the child the ultimate diagnosis is evolving.

The coordination of the therapies with the school program is one of the areas noted by both therapists and teachers we have talked with at this workshop where ideas and models are needed. The program at Meyer Children's Rehabilitation Institute is one example of how centers are approaching this goal. All three therapies--speech, occupational and physical therapy--have program time in the nursery school, supplementing and paralleling what these departments do in working with children and parents. Physical therapists have two chief concerns, (a) physical management or therapy carryover for the handicapped or motor delayed child in the nursery school, and (b) sensory and perceptual-motor training in the nursery school setting.

Physical therapy carry-over goals in the nursery school include:

1. Giving the child the opportunity to practice and support skills acquired and learned in therapy and home program-- balance, locomotion, agility skills, and postural background patterns of the arms necessary for manipulation.

2. Prevent deformity and deformity-producing patterns which may be worsened by child's immobility, by stereotyped postures, or harmful movement patterns.

3. Assist planning or modifying furniture or equipment for nursery school use -- chairs, standing equipment, transportation, playground, toys and sensory stimulation according to needs of individual children. A carry-over sheet is filled out for each child and interpreted and demonstrated to the teachers and aides. These help the school personnel

know what to expect the child to do and how he should do it, as well as what he should not do. It is desirable to have individual instructions for each child as the developmental pattern may be helpful for one child and serve to increase abnormality in another. General principles can also be given the school staff that they might apply in another situation where there are no specific guidelines by a therapist.

All the children in the nursery school participate in a perceptual-motor development program geared to individual and group needs. Physical Therapy goals are: (1) Improve balance and agility skills emphasizing daily living functional skills such as climbing stairs, sitting on a chair, as well as use of play equipment socially important to a child. (2) Encouraging the development of body perception needed for efficient movement and to give the child a basis for spatial and directional concepts, and (3) develop "aware movement or thinking and movement" also called motor planning or praxia. We want a child to know what he is doing -- many children run, jump, climb and have lots of movement, but when asked to imitate a certain movement or to follow a verbally instructed movement they cannot. These skills are important in a school setting, in learning many self-help skills, and are closely related to the awareness and control of movement needed in various communication techniques used with the deaf-blind child. Written lesson plans are provided and demonstrated in the classroom and the therapists assist the teachers in assessing their groups with developmental checklists and in the prescriptive curriculum.

SUMMARY OF RECOMMENDATIONS: It was not felt that we could at this time plan a common evaluative battery or remedial program to be used in the various deaf-blind programs. The needs that were felt to be of first priority were:

1. Continuing education of other disciplines involved in management of the deaf-blind was still needed as to how to utilize physical or occupational therapists in their programs.

2. A physical therapist and/or occupational therapist, or consultant for the regional deaf-blind program was suggested to help therapists and programs without therapists.

3. Therapy workshops or training visits to programs meeting special needs of therapists were suggested.

4. Training visits for teachers and participation of therapists in teaching workshops were suggested.

THE ROLE OF SOCIAL WORK IN ASSESSMENT OF THE FAMILY AND CRISIS INTERVENTION PROCEDURES FOR COUNSELING PARENTS OF DEAF-BLIND CHILDREN

June L. Horsley

The intent of this paper is not to review the rubella syndrome or to elucidate upon the penumbra of characteristics or behaviors, or the special needs of the deaf-blind child.

This paper, will instead, be limited to outlining the functions and the structure of a family under "normal" circumstances to be used as a frame of reference for assessing and counseling those families experiencing crises situations. It will also be the intent of this paper to delineate some specific measures of crisis intervention as suggestions by way of counseling with the parents of a visually and aurally handicapped child.

The Family: The term "the family" is an emotion-laden term subject to many definitions and to unlimited individual perceptions. Especially today, when the contemporary family is tending toward egalitarian roles and is a group in transition, numerous perceptions of "the family" exist.

For the purpose of this paper, however, the family will be described as a small group whose primary function is the transmitting of essential mechanisms of socialization which lead to the cuture's norms of social order. This small group provides the major source of the values and attitudes that people hold, and is an important factor in pressures to conform to social norms. There is little doubt that the family unit is the perpetrator of certain roles which children learn and later carry into other life situations.

Other important concepts of the responsibilities of the family, as a small group, are understood through examination of the process of group formation and the establishment of group identity.[1] For instance, the family gains cohesiveness and security (feeling of belonging) for its members through actively participating together in the determination of group goals. Group goals emerge out of individual goals, beginning with the marriage of two people and their formation of a nuclear family. Marital partner goals later become that of socialization of the children

born to that union. Elements of group formation and group identity stem most often from the initial type of structure that is established by members of the group--in relation to, and involvement of, expected ways of proceeding with family plans, rules, decision-making (implicit and explicit) and clarification of roles within the group.

The "healthy" family is not only capable of setting up group controls and distributing authority, but is also flexible enough to accommodate to changes in structure, role expectations, purposes and general functioning and in changing needs and capacities of its members.

Family structure is assessed in the light of family membership and is based on recognition of the family composition and the performance of family functions. The structure must be evaluated on the completeness of personal resources which the two-generational family can optimally provide, for both spouses and siblings, which lead to a feeling of unity and mutual, purposeful cooperation. The spouses have to learn to meet each other's needs until they have achieved emancipation from their own childhood ties to a degree that enables them to assume the roles and responsibilities of parenthood.[2] They then must learn to meet the dependency needs of their children in order to insure the children's maturity and growth. This process requires a period of time in which the closeness between the spouses is loosened somewhat so that the necessary close relationship between parent and child can develop. Later, this relationship must be loosened also, as the child matures.

The relationships and interactions between sibs is also of importance in that it provides them with support from their own generation within the family setting. If the sibs are not of the same sex, they provide one another with an awareness of bisexuality in the sharing of the home and their parent's affections. Here as well, however, there must be an eventual loosening of the relationship in order for the children to draw apart and become independent, well-functioning adults in their own right.

In certain aspects of family formation and family identity, family structure runs a parallel course in importance with family functioning and role performance. In the spouse system (Pollak, 1960)[3] the marriage partners meet the needs of the other "through performance of functions described as emotional, sexual, economic and ego-strengthening" roles. This is a mutual assistance system in the maintenance of emotional security on an adult level, and provides for the individual's feelings (needs) for biological and social completeness. "They give one another an opportunity for non-pathological regression, the security of receiving tenderness and consideration, provision of care, and the experience of a spectrum of common interests."[4]

The spouses eventually attain a mutually agreed upon functioning in regards to division of labor and the utilization of income. In the areas of ego-support and ego development of the spouses, each aids the other in strengthening adaptive mechanisms of defenses and in helping

each other learn the marital and parental roles they have assumed. The parents promote maturation of the children through physical and emotional nurture and through interpersonal relationship skills in the process of socialization. They assist their children in the development of adequate ego functioning and superego formation and later provide experiences outside the family which will lead to the children's emancipation and achievement of separate identities in adulthood.

Admittedly, the above statements are idealistic in nature and in actuality, too few families attain such processes in totality. However, it is a frame of reference, and a diagnostic tool for assessing deviance and/or distortions of basic family functioning. We should take especial note of these factors as we assess the family undergoing a crisis situation--indicating what areas the family participants have not reached this level of maturity or attained this kind of security in the reciprocity of roles, etc. We should take especial note of those families who appear to be too rigid (insecure) to adjust to the birth (or the residential placement) of a handicapped child. We should know, in depth, those families who have not established homeostatic mechanisms which allow for release and for regaining equilibrium.

Before the Crisis: The initial parental reaction to the confirmation that the mother is indeed pregnant is usually one of heightened awareness and expectations for a new human being--perfect in health and brimming over with potential for achievement throughout a long life. During the entire gestation period, however, the mother experiences increasing strain and narcissism as she undergoes somatic and psychological changes. Under normal conditions of pregnancy, these pressures continue after the delivery of the infant and disappear only gradually, in reciprocity with the child as he grows and develops.[5]

The Crisis: This gradual dissipation of anxiety and its resultant increase of pleasure in giving birth to a healthy baby is denied the parent of a handicapped child. In this instance, the heightened emotionality of the father, in response to that of the mother, and as a result of his own anxiety, is also denied normal release. Bowman and Yoder (1966)[6] report that the parents, even with a suspicion of a handicapping condition, enter a period of sustained anxiety. This can begin while the mother is still in the delivery room. For example, when pregnancy and delivery events follow the expected pattern, the mother feels pride in her accomplishment. This results from the immediate feedback she receives from the doctor, the hospital staff, her husband, family and friends. Her rewards for producing a healthy child are many and instantaneous. She feels a closeness and an increased amount of interaction with the child. The presence of a healthy, "normal" child can be acknowledged openly and future plans and expectations for the child elaborated upon by all.

But, when the mother gives birth to a defective child (even if she anticipated some sort of complications), she is never fully prepared,

emotionally, for this final declaration that she has a handicapped child. This scene too, is set in the hospital. There is often a general pervasive apprehensiveness on the part of the staff, the mother is often isolated from those mothers who have given birth to "normal" children; often there is no prompt and frank discussion of the child's disabilities, by the doctor or the staff, with the parents of the afflicted child. Thus, these parents must frequently bear their anguish alone.

> "The birth of a congenitally defective child transforms a joyously awaited experience into one of catastrophe and profound psychological threat. The apprehension of failure that is a normal part of the psychic anticipation of parenthood turns into reality--and the family finds itself in crisis."[7]

The parent's reactions to the baby and their relationship with it are often dependent upon the kind and degree of the handicapping conditions. In any case, the reactions include, to one degree or another, feelings of shame, anxiety, guilt and hostility as well as attitudes of defensiveness, self-recrimination and self-pity. Parents may isolate themselves and the child through ignorance or over-protectiveness of their child or of their own egos.

Other authors relate that the birth of a handicapped child implies an automatic rejection of that child by the parents. Kirk (1964)[8] puts forth this hypothesis, positing that it is a most difficult task for the parent to accept a defective child--especially so at the time that the handicaps are first discovered. Ayrault (1964)[9] agrees, saying that if the handicap is apparent at birth, it can be a most traumatic shock and can be accompanied by strong feelings of revulsion and rejection. It creates anxiety, guilt and often panic.

Hutt and Gibby (1965)[10] have found that parents, upon learning that their child is handicapped, choose one of three common reactions: 1) they may be accepting of the child; 2) they may be denying and rejecting of the child; or 3) they may disguise and deny their own feelings. These authors feel that the personality reactions of the individual parents are influenced by the emotional stability of that individual, the stability of the family interactions and relationships and the social-cultural pressures of the community of which they are a part.

A step further, in describing what processes must be undertaken by the family in its attempts to regain homeostasis after the birth of such a child, are presented by Egg (1964).[11] Three stages are examined as crisis-adjustment steps: 1) the initial stage--the "I-Centered" stage when the parents go through a mourning period. A time which is usually filled with self-pity when the parents ask, "Why did this have to happen to me? Why must I be punished this way?" 2) The second stage

is the "Child-Centered" period when the parents ask, "What can I do for my child?" During this period, the parent searches for cures and services for aiding the child. 3) The third stage is called the "Community-Centered" stage when the parent joins community groups to help all handicapped children.

In reviewing these three stages in more detail, consider these in the light of being applicable to the universal steps through which the parents of a deaf-blind child must progress. First, the stage of "I-Centeredness" and the associated process of grieving (mourning). Symptomotology of grief and mourning include the following syndrome: sensations of somatic distress occurring in waves lasting from twenty minutes to an hour at a time, a feeling of tightness in the throat, choaking with shortness of breath, need for sighing, an empty feeling in the abdomen, lack of muscular power and an intense subjective distress described as tension or mental pain. [11]

In periods of grief, the sensorium is generally somewhat altered. There is commonly a sense of unreality, a feeling of increased emotional distance from other people (at times, they actually seem shadowy or small) and there is an intense preoccupation with the image of the afflicted child. The parent is obsessed with feelings of guilt and searches his soul for evidences of negligence or exaggerates minor omissions for some preceding period of time. In addition, some individuals experience marked swings of moods ranging from withdrawal to hostility toward oneself and toward the world in general, to no retardation in action, a rush of speech, a restlessness or aimless moving about searching for something. At these times, there seems to be a loss of the past patterns of conduct and social interaction.[12]

In normal grieving and mourning reactions (i.e. such as in the death of a loved one), it can be anticipated that the mourning period will last approximately six to eight weeks. In the case of parents grieving the birth of a handicapped child (the "loss of a pe fect" child), an entirely different phenomena faces them. The crisis situation and its concomitant immobilization is not just a "one time occurrence". But instead, there are repeated or a series of crises continually confronting this family. There is also sustained ambivalence, hostility, guilt and anxiety on the part of these parents because they are faced daily with the problems of management of this defective child--while at the same time, they are denied and deprived of the opportunity to project any of the blame for the problems onto the child himself. When families are disrupted by problems arising from emotional or deviant behaviors on the part of the children, and which result in disturbed parent-child relationships, the parents can blame the child for a part of the problem--thereby alleviating themselves of a portion of their parental guilt.

Crisis Intervention: Due to the special circumstances involved in counseling the parents of a handicapped child and because of the difference in parental attitudes and emotional threats, as well as the constant

presence of the afflicted child and the daily reminders of his limited capabilities, it is suggested that counseling of these parents be held in two phases: 1) immediate crisis intervention procedures, and 2) long-term counseling sessions. [13]

Immediate crisis intervention measures should include: 1) A rapid and accurate assessment of the strengths and weakness of all family members, the kinds of relationships existing in the family and the extent of damage done to the egos of the parents producing the handicapped child. 2) Focus on the immediate emotional distress of the parents, their capacity to express anger, resentment and guilt feelings. 3) Attend early to the practical and realistic problems that require solving right NOW (food and meals for the family, care of the other sibs, referral to medical or other service agencies. 4) Encourage ventilation of feelings--"let it all out". It is important to let the parents know that their feelings of grief are normal and that it is all right for them to express their anger and sorrow. 4) Working through the feelings the parents are experiencing (beginning as soon as possible and extending over a period of time). A review of forty parents who had given birth to defective children, reveals that the parents need time to take in the extent of their problem and start working on realistic solutions. 5) Give support and reassurance as appropriate to the situation (i.e., point out the areas in which the parents are successfully coping--such as continuing their parenting roles with the other children, etc.). 6) To ameliorate the guilt of the parents, counsel them <u>together</u> and focus on the mutuality of feelings shared by them both. This not only helps restore the marital balance but also helps the parents focus on their mutual concern for the child--enabling them to put forth combined efforts to handle the crisis situation. 7) Answer questions about the child and his problems as they arise. Parents do not raise questions in an orderly, crystallized fashion, but gradually, as the child grows (or fails to grow).

Hopefully, the social worker and the parents are now at the point where the second stage of the mourning process, the "Child-Centered" stage and the long-term counseling sessions are appropriate (except for those times of recurring crises). There is much overlap in both the stages that the parents go through as well as the progress of the counseling. The worker should be cognizant of these determinates of need for long-term counseling: 1) recurring periods of stress and crisis caused by the overwhelming problems of management of the deaf-blind child. 2) Recognition, that with a defective child in the family, the family functioning or relationships cannot remain static, nor can it ever be reconstructed in the way that it was before the catastrophe struck them. 3) Therefore, the family must have help in making the changes which are now demanded of them because of the special needs of the defective child. Counseling sessions need to be directed toward helping the parents see that their attitudes and feelings toward defective children per se, have possibly shifted their own parental behaviors. 4) Help work through all problem areas that arise under continued pressures and frustrations such as marital discord, upset siblings, the increased dependency of the handicapped child on the parents, the crumbling of parental expectations for

the defective child, confusion and lack of definiteness of medical diagnosis, training and discipline and rehabilitation of the handicapped child--to name a few. 5) Long-term family sessions (and "family" here means including all family members in the sessions so that they too have opportunity of verbalizing their feelings as well as acknowledging that they are important members of the group) are also recommended because families with deaf-blind children often experience extreme weariness, frustration, uneasiness and impatience with the slow developmental progress of the defective child. The "slowness" of the defective child may also affect the social worker and she may fail to support the parents' efforts adequately, or she may project the blame onto the parents for the child's failure to "move". She may also blame the parents for failing to utilize the counseling she has provided. In such instances, the worker should take a close, objective look at her own feelings of inadequacy and frustration. 6) Long-term counseling affords the social worker the opportunity to give the parents educational information regarding child development or what community resources to contact for services. It also gives the afflicted child the opportunity to respond and develop at his own rate and speed--while at the same time, the parents can learn management techniques for the changing behaviors of the child. 7) Extended contact with the family enables the worker to help the parents see the actual progress that the handicapped child has made. Without observations from an "outsider" the parents may not be aware of the child's progress.

This phase of counseling can very often involve the necessity of working through separation problems of the parents and of the handicapped child, if placement of the child in a residential institution is indicated.

In working through separation, the social worker should take cognizance of how the parents have dealt with separations in the past. Information needed in making this assessment should include: 1) knowledge of the individual's dependency needs and how they have been met in the past, 2) is the family over-protective of the handicapped child and, if so, for what reasons, 3) what dependency needs has this child met for the mother, the father and the family, 4) what role has the afflicted child played in the family, 5) if the child is removed from the family, who will not play that role or meet those needs, 6) what other family roles will change as a result of the loss of this child, 7) what changes in life style will the family now experience, 8) what adjustments will need to be made because of this change in life style? The questions could go on, but the basic reason behind such questioning is that the meaning of the placement for the child must be viewed through the eyes of the parents and through the eyes of the involved child, <u>not</u> through the eyes of the worker.

For the child, separations from home and family can be the cause of phobias, aggressive behavior, withdrawal, fear and anxiety, feelings of abandonment and desertion, loss and rejection and anger. The parents may again experience the fear of being failures as parents, as well as having all their old anxieties, inadequacies and self-doubts reactivated.

To alleviate as many of these fears as possible, the worker must: 1) encourage the parent (and the child, if he is capable of comprehension) to keep repression at a minimum (i.e., to verbalize the fears and concerns openly), 2) regarding the placement site, encourage the parents to make pre-visits and supply them with as much descriptive information concerning the placement as possible, 3) encourage the personnel at the site of the placement to minimize surprises for the child in the new environment, 4) immediately after the child has been "placed" the worker should become "over-available" to the parents (or to the child) for a period of time, 5) the worker should take the responsibility of reporting to the parents the development and progress being made by the child and should encourage the parents' continuing involvement with the child while he is in his new environment.

Work with the parents regarding the placement of the child should begin far in advance of the actual placement so that the parents will feel involved in the decision-making and in the placement procedures. It should not be forgotten that each time the child returns to the home for visits or vacations, the return to the residential placement may bring a resurgence of any or all of the above factors with the concomitant needs for attention.

The stage of parental adjustment--"the Community-Centered" stage--has been touched on, only tengentially in this paper. This aspect will have to be explored in more detail at a later time. However, it should be acknowledged that joining community groups for the purpose of helping other handicapped children, can be a rewarding and "eye-opening" experience for these parents. Often, while sharing their problems with other parents, the realization is brought home to them that others are more burdened than they.

It must also be said that far too often, parents of these children are still finding little understanding and are receiving far too little assistance from physicians, teachers, social workers and social agencies.[14] Parents are asking for more (and earlier) information about their child's handicapping conditions, they are asking for comprehensive plans for locating and receiving various types of services for their child, they are asking "to be listened to" for they also know a great deal about their child. At the same time, they are asking the professional to guide them through the seemingly hopeless maze of services in the community. They are also asking for local services for their child so that the long distances they have had to travel in the past will be eliminated.

How will be answer these parents?

FOOTNOTES

1. Grace L. Coyle. "Concepts Relevant to Helping the Family as a Group," Social Casework, Vol. 43, No. 7, (July, 1962), pp. 347-350.

2. Otto Pollak. "A Family Diagnosis Model," Social Service Review, Vol.34, No. 1, (March, 1960), pp. 19-28.

3. Ibid., p. 23.

4. Pollak. loc. cit.

5. Lawrence Goodman. "Continuing Treatment of Parents with Congenitally Defective Infants," Social Work, Vol. 9, No. 1. (January, 1964),p.92.

6. Maurice Tretakoff. "Counseling Parents of Handicapped Children: A Review," Mental Retardation, Vol. 7, No. 4, (August, 1969), p. 31.

7. Goodman. loc. cit.

8. Samuel A. Kirk. Educating Exceptional Children, Boston: Houghton Mifflin Co., 1962, p. 290.

9. Evelyn W. Ayrault. You Can Raise Your Handicapped Child, New York: G. P. Putnam's Sons, 1964, p. 128.

10. Max L. Hutt and Robert G. Gibby. "Parental Reactions" in The Mentally Retarded Child: Development, Education and Treatment, Boston: Allyn and Bacon, 1965, p. 292.

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12. Howard J. Parad (Ed). Crisis Intervention: Selected Readings, New York: Family Service Association of America, 1965, p. 10.

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REPORT OF SOCIAL SERVICE GROUP

To get some sensitivity to the world of the deaf-blind child, members of our group paired up, one becoming a "deaf-blind" person with the aid of ear plugs and closed eyes and the other becoming the sighted helper. . First the "handicapped" were led, then were given instructions by taps on the back. Feelings experienced during the exercise were tenseness, anxiety, frustration, anger, dependency, helplessness. This technique might be useful for selected parents of deaf-blind children.

Who should talk with parents of children being seen in a multidisciplinary setting? The professional who has established the closest relationship with the family and/or the professional who has expertise in the area of major concern for the development of the child seem to be most appropriate resource. Teacher and social worker, by putting their heads together can communicate more effectively with parents about a child's progress in the classroom and about follow-through necessary at home.

There is need for standardization of a social history for deaf-blind children so that longitudinal studies of these children can be constructed and data can be readily compiled. Perhaps these histories will involve computerization in the future. Information in the social history on a deaf-blind child should include the parents' perception of the child's visual and hearing abilities and the parents' ideas about their child's potential. Discrepancies between the parents perceptions and the child's apparent abilities should be carefully noted.

There have not been as many referrals to the deaf-blind program as expected, possibly because of midunderstanding of what kind of child is eligible. Personal contact with agencies to clarify the type of services being offered and the kind of referrals desired is invaluable to casefinding. Work with deaf-blind children may move toward stimulating better services to all multiply handicapped children.

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