
California State Dept. of Education, Sacramento; Southwestern Region Deaf-Blind Center, Sacramento, Calif.

Office of Education (DHEW), Washington, D.C., 79.

MF01/PC04 Plus Postage.

*Auditory Evaluation; Communication Skills; *Deaf Blind; Elementary Secondary Education; Etiology; Hospital Schools; *Identification; *Intervention; Medical Treatment; Motor Development; *Multiply Handicapped; Parent Counseling; Preschool Education; Severely Handicapped; Therapy

The document contains 11 papers presented at a workshop sponsored by the Southwestern Region Deaf-Blind Center on the identification, assessment, and training of the deaf blind and multiply handicapped child. Entries include the following titles and authors: "Auditory Assessment of the Multihandicapped Deaf-Blind Child" (auditory evaluation of children with hearing, vision, and other handicaps) by R. Sweitzer; "The Deaf-Blind Child as a Visually Functioning Person" (visual functions, physiology, and assessment) by R. Seelye; "Multiple Handicaps: A Developmental Approach to Their Assessment" (biological and environmental determinants of handicaps) by V. Holm; "Corrective Therapy for the Deaf-Blind and Multihandicapped Individual: Identification, Developmental Assessment, and Training" (definitions and procedures of corrective therapy, application of medically oriented physical education principles) by G. Granberry; "Communication with Deaf-Blind Children" (communication needs and sign language) by M. Sternberg; "A Total Approach for Increasing the Quality of Life for the Visually and Auditory Impaired Child" (a method of assisting the primary caretaker in the role of teacher) by S. Meyer; "Parent Counseling" (techniques in parent counseling and the roles of the professional) by B. Mills; "Medical Crisis Intervention" (health professionals and the interdisciplinary team, and management of medical problems in the classroom) by P. Ziring; "Fine Motor Skills for the Classroom" (developmental steps of the motor skills) by G. Granberry; "Hospital Stimulation Programs" (educational services in hospitals for deaf blind and multihandicapped preschoolers) by M. Appell; and "Therapy Techniques with Deaf-Blind Children" (roles of the occupational and physical therapists) by B. Scanlan. (SBH)

* Reproductions supplied by EDRS are the best that can be made from the original document.
This publication, which was funded under the provisions of Public Law 91-230, Title VI, Education of the Handicapped Act, Part C, Section 822, was published by the California State Department of Education, 721 Capitol Mall, Sacramento, CA 95814. The activity which is the subject of this publication was supported in whole or in part by the U.S. Office of Education, Department of Health, Education, and Welfare. However, the opinions expressed herein do not necessarily reflect the position or policy of the U.S. Office of Education, and no official endorsement by the U.S. Office of Education should be inferred.

Printed by the Office of State Printing
and distributed under the provisions of the
Library Distribution Act
1979
Contents

Preface ........................................... v

Auditory Assessment of the Multihandicapped Deaf-Blind Child ......................... 1
  Richard S. Sweitzer, Associate Director, Division of Audiology, Joseph P. Kennedy, Jr., Memorial Hospital for Children

The Deaf-Blind Child as a Visually Functioning Person ......................................... 14
  Roger R. Seelye, Clinical Director, Pediatrics Low Vision Clinic, Michigan School for the Blind

Multiple Handicaps: A Developmental Approach to Their Assessment ..................... 23
  Vanja Holm, M.D., Assistant Professor in Pediatrics, University of Washington School of Medicine

Corrective Therapy for the Deaf-Blind and Multihandicapped Individual: Identification, Developmental Assessment, and Training .......................... 33
  Georgia L. Granberry, Program Coordinator, Ellisville State School Residential Deaf-Blind Program

Communication with Deaf-Blind Children ................................................................. 36
  Martin L. A. Sternberg, Deafness Research and Training Center, New York University

A Total Approach for Increasing the Quality of Life for the Visually and Auditorily Impaired Child ................................................................. 39
  Sandra Meyer, Consultant, Education of Deaf-Blind Children, John Tracy Clinic

Parent Counseling ............................................. 47
  Barbara Mills, Psychologist, John Tracy Clinic

Medical Crisis Intervention ......................................................................................... 52
  Philip Ziring, M.D., Assistant Professor of Pediatrics, College of Physicians and Surgeons, Columbia University, and Medical Director, Willowbrook Developmental Center

Fine Motor Skills for the Classroom ................................................................. 55
  Georgia L. Granberry, Program Coordinator, Ellisville State School Residential Deaf-Blind Program

Hospital Stimulation Programs ............................................................................. 59
  Madeline W. Appell, Assistant Professor of Clinical Pediatrics, College of Physicians and Surgeons, Columbia University; and Chief, Child Development Section, The Roosevelt Hospital

Therapy Techniques with Deaf-Blind Children ...................................................... 65
  Betty Scanlan, Physical and Occupational Therapy Supervisor, West Suburban Association for the Hearing, Orthopedically, and Visually Impaired, Lombard, Illinois
Preface

The Southwestern Region Deaf-Blind Center, in anticipation of the changes that were about to be made under Public Law 94-142, made a decision in 1977 to invite those who work with the multihandicapped children to attend its workshops. The first of such joint efforts was held from September 13 through September 18 in Honolulu, Hawaii, to discuss the identification, assessment, and training of the deaf-blind and multihandicapped child.

Every effort was made to bring to the Hawaii workshop the most knowledgeable speakers in the various disciplines. During the six-day session, a number of experts presented papers on topics ranging from auditory and visual assessment to infant stimulation, parent counseling, and other concomitant subjects that affect deaf-blind children.

Along with some of the previous publications of the Southwestern Region Deaf-Blind Center, this particular publication is rich in content and may be useful for instruction in teacher training programs. Moreover, the publication should be of great help to those who are searching for information to use in providing better services both to the multihandicapped and to the deaf-blind.

DAVIS W. CAMPBELL
Deputy Superintendent
for Programs

WILLIAM A. BLEA
Director
Southwestern Region Deaf-Blind Center
Please complete the Readership Survey on page 69 at your earliest convenience and return to Southwestern Region Deaf-Blind Center, California State Department of Education, 721 Capitol Mall, Sacramento, CA 95814.
Auditory Assessment of the Multihandicapped Deaf-Blind Child

Presented by Richard S. Sweitzer, Associate Director
Division of Audiology
Joseph P. Kennedy, Jr., Memorial Hospital for Children, Brighton, Massachusetts

This paper is intended to provide basic information on the auditory evaluation of youngsters with hearing, vision, and other handicaps. My experience with these handicapped children was obtained primarily through consultation activities with the Massachusetts Association for the Blind and its residential training program for the deaf-blind multihandicapped. Most of the children in the program are handicapped as a result of the maternal rubella epidemic which struck Massachusetts in 1974. I first started working with these children in 1976 and have followed many of them since they were eighteen to twenty-four months of age.

The involvement of the professional in the assessment of these youngsters is extremely important because he or she is able to follow the children at the "grass roots" level for long periods of time. Unfortunately, my involvement with each youngster has been for only an hour at intervals of two to three times a year.

The informal assessments by parents and childcare workers also provide extremely valuable information for use by the consulting audiologist. These evaluations have to be ongoing, or at least on a daily basis.

A good working relationship should be developed with a consulting audiologist who can provide technical, diagnostic, and therapeutic information. The audiologist should have considerable experience in working with young children, particularly the low-functioning child. The audiologist should be willing to see the child in other than a clinical setting, for example, he or she should be willing to go to the child's home or school because the multihandicapped youngster is often upset by changes in his or her environment. When testing is completed in surroundings familiar to the child, the tester is able to observe more typical behavior and response patterns.

This discussion is divided into three parts. The first part deals with terminology that will provide a common basis of understanding. I do not plan to spend a great deal of time in detailing the physics of sound, or the anatomy and physiology of the auditory system. Some excellent texts in basic and advanced audiology are given in the list of references at the end of this paper.

The second portion of the discussion deals with the professional's personal involvement in assessing the hearing of the multihandicapped. As previously suggested, the consultant audiologist relies heavily on input from other people who work with the child. These people should be able to make careful and detailed observations of the youngster's auditory behavior.

Finally, the third part deals with formal audiological evaluation in the clinical setting.

Terminology

The following are terms used most frequently in audiological evaluation work:

Frequency - The number of sound vibrations produced per second. The psychological attribute is pitch. Frequency is measured in units of Hertz (Hz). The frequency range of the human ear is approximately 20 to 20,000 Hz, but in clinical audiology hearing is assessed only at those frequencies most important to the understanding of speech (100 to 8,000 Hz).

Intensity - The psychological attribute of loudness, which is measured in decibels (db). The decibel is a relative measurement, and in this discussion the reference point will be 0 db normal hearing, as based on the 1969 ANSI standards. The range of normal hearing is from the softest intensity that can be heard (0 db) to the threshold of discomfort and pain (120 to 130 db).

Spectral characteristics - The psychological attribute of quality. It is the interaction of a number of different frequencies at different intensities as would be found in a complex sound. The same note sounded on a piano and viola have their own unique quality: the spectral characteristics
of the sound give these two instruments their own quality.

**Audiogram** - A plot of hearing level in db as a function of frequency (Figure 1).

**Air conduction** - A pure tone hearing test that is administered with earphones. The test is used to assess the entire auditory system.

**Bone conduction** - A pure tone hearing test that is administered with a bone conduction receiver placed against the skull. The test is used to assess only the cochlea and higher auditory centers.

**Conductive hearing loss** - A hearing impairment secondary to abnormal conditions in the outer or middle ear (air-bone gap present) (Figure 2).

**Sensorineural hearing loss** - A hearing impairment secondary to abnormal conditions in the cochlea and/or the VIII cranial nerve (no air-bone gap) (Figure 3).

**Severity of hearing impairment** - A categorical description of different degrees of hearing impairment (Table 1).

### Table 1

<table>
<thead>
<tr>
<th>Hearing level in db (1969 ANSI)</th>
<th>Descriptive category</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20</td>
<td>Normal</td>
</tr>
<tr>
<td>21-35</td>
<td>Mild</td>
</tr>
<tr>
<td>36-55</td>
<td>Moderate</td>
</tr>
<tr>
<td>56-70</td>
<td>Moderately-Severe</td>
</tr>
<tr>
<td>71-90</td>
<td>Severe</td>
</tr>
<tr>
<td>90 plus</td>
<td>Profound</td>
</tr>
</tbody>
</table>

The reason why a mild or moderate hearing loss can have a deleterious effect upon the normal acquisition of speech and language must be considered. Speech is characterized by two primary elements: consonants and vowels (Table 2). Vowels characteristically carry more low-frequency energy than consonants; for example, the vowel /a/ (as in paw) has frequency components as low as 130 Hz in the male voice, while the consonant /b/ (as in thin) has frequency components in the region of 3,500 Hz and above. Furthermore, for a given amount of vocal effort, vowels carry more intensity than consonants; for example, the vowel is the most intense speech sound in the English language, but for the same amount of vocal effort the consonant is approximately 29 db less intense.

### Table 2

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Interval</th>
<th>Time</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consonants</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vowels</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If a person has a predominantly high-frequency hearing loss with relatively normal low-frequency residual hearing, the vowels can be heard relatively well, but the less intense high-frequency consonants are more difficult to hear. Unfortunately, the consonant sounds carry the most information for understanding speech, while vowels contribute little to understanding. If, for example, the vowels are taken out of a reading passage (leaving the consonants), one can get a general idea of the message. When the consonants are removed from the same passage, intelligibility is negligible. Thus, the hearing-impaired individual who can hear primarily vowels has great difficulty understanding speech.

### Grass Roots Evaluation

As much information as possible should be gathered at the grass roots level on the auditory status of the child. Considerable time and patience is needed to accomplish such a task; therefore, one should not expect to obtain reliable or valid information, even when the child is seen at least two times per day over a period of six months. To make the task simpler, more organized, and more viable, certain factors must be considered.

### Test Environment

First, the test environment must be taken into consideration. Testing should be completed in a room which is out of the mainstream of traffic and which will preclude interruptions by other staff or children. The room need not be large, but it should be big enough to accommodate two staff members, a child, table and chairs, and miscellaneous equipment such as a phonograph, tape recorder, and piano. At the Massachusetts Association for the Blind, the same room is used for music therapy. The room should have some minimal acoustical treatment; that is, carpeting on the floor, acoustical ceiling tiles, and heavy draperies to cover the
Fig. 1. Audiogram for normal hearing

Fig. 2. Audiogram for conductive hearing loss
windows. The most important consideration for the room is minimizing, as much as possible, extraneous noise and reverberations (echoes). Any extraneous noise can invalidate observations, and the presence of echoes can make it difficult to calibrate the intensity level of the signals.

In addition to acoustical considerations, some thought should be given to the lighting characteristics of the room. The “blindisms” of light gazing and hand flapping by the visually impaired child should be avoided as much as possible. Thus, a dimmer switch might be installed to reduce light. Lighting should be sufficient, however, so that the child can be clearly observed.

The physical comfort of the child is extremely important. The child should have gone to the toilet, should be wearing comfortable clothing, and should not be too fatigued. Testing should not be conducted immediately following a meal, particularly if food reinforcement is to be used. The child should be observed over several days to determine at least one time period during the morning and afternoon when he or she appears to be best suited for testing. The initial testing periods should last no longer than 15 to 20 minutes.

Test Personnel

Two people should be present for each test session. Duties can be alternated between the two individuals, but one person must assume responsibility for the presentation of signals, and the other should be responsible for observing. For the tester, it is most important to remember that he or she should be located out of the child’s peripheral vision when sounding noise makers. The tester should avoid casting any shadows. Generally, the tester should not be able to see the child’s face.

In addition to avoiding visual cues, the tester should also attempt to avoid vibratory cues which might be produced by a loud drum or a low note on a piano.

The timing of the presentation of signals is important. Signals should not be presented at regular intervals and, when presented, should have

![Fig. 3. Audiogram for sensorineural hearing loss](image-url)
a duration of at least 3 to 5 seconds, unless a quick startle response is needed. Signals should be presented when the child is in an apparent ready-to-listen state. The characteristics of such a state are difficult to describe, but the child should not be light gazing, hand flapping, moving about, or involved in any other activity. The observer can assist in gaining the child's attention by sitting in front of him or her and holding his or her hands or legs. Through the use of verbal or hand signals, the observer can tell the tester when the child has adopted a ready-to-listen attitude, and the signal can then be presented.

Prior to auditory testing or at the beginning of each session, one should evaluate the child's responsiveness to tactile and visual stimuli. The child's reactions to touch should be tested by tapping the child lightly on the shoulder. Does the child withdraw or reach for the observer's hand? If no response is observed, the intensity of the tapping should be increased. Finally, the child should be pinched. If the child does not respond to pinching, it is unlikely that he or she will respond to auditory stimulation, and further testing would be a waste of time.

The child's reaction to vibration should also be determined. A bone conduction receiver similar to that used on an audiometer can be placed on a high-gain, body-level hearing aid. When the instrument is turned to maximum volume, the receiver should vibrate. If an audiometer is available, the instrument should be set to bone conduction and the output adjusted at 250 Hz to the maximum level (usually 40 to 45 db) so that the receiver vibrates. The audiometer can also be set at 500 Hz with an output of 65 to 70 db, and again vibration should be noted. A signal should be presented with the bone conduction receiver in the child’s hand. Does the child withdraw or adopt an inquisitive attitude toward the vibration? If vibrotactile stimuli cause behavioral changes, it is likely that good responses to auditory stimuli will be obtained if the child is able to hear.

Evaluation Equipment

The minimal amount of equipment needed for informal evaluations is listed in Table 3. The otoscope is of extreme importance for observing the ear canal. If the ear canal is occluded with wax (cerumen), and if there is drainage from the ear, testing should be stopped until medical attention can be obtained. The outer ear and the ear canal of those children using hearing aids should be checked. The ear mold to the hearing aid should

<table>
<thead>
<tr>
<th>Otoscope</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loud voice</td>
</tr>
<tr>
<td>Bells</td>
</tr>
<tr>
<td>Horns</td>
</tr>
<tr>
<td>Drums</td>
</tr>
<tr>
<td>Rattles</td>
</tr>
<tr>
<td>Audiometer</td>
</tr>
<tr>
<td>Piano</td>
</tr>
<tr>
<td>Phonograph</td>
</tr>
</tbody>
</table>

Table 3: Equipment Needed for Informal Evaluations

not cause irritation to the ears. Also, the child who uses a hearing aid during all of his or her waking hours has a greater chance of accumulating undue amounts of cerumen, which could interfere with effective hearing aid performance.

For the best results, testing should be started with the youngster using his or her hearing aid, if he or she is accustomed to the unit. Once positive responses are elicited with the use of the hearing aid, one can then attempt unaided testing. The testing program should be coordinated with any auditory training provided by the teacher who may be useful as an assistant.

A supply of various noise makers and a strong voice are important to the testing. All of the noise makers should be spectrally analyzed by the consultant audiologist (Bove and Flugrath, 1973). This analysis can be performed by most audiology clinics, and the frequency and intensity characteristics of each noise maker must be specified. The person who administers the tests will need to know the intensity level in decibels of the noise maker when it is sounded at loud, moderately loud, and soft levels. Although it takes considerable practice and experience, it does not take long to learn to sound the noise maker and to estimate the approximate intensity.

One should also have his or her voice analyzed. The average shout is at a hearing level of approximately 85 to 95 db; the average conversational voice is at a hearing level of 50 to 60 db; and the hearing level of a soft whisper ranges from 25 to 35 db when presented at a distance of not greater than 3 to 4 feet from the ear.

Sounds which are likely to yield the most positive response should be used during the initial session. Generally, the more complex signal provides the better response. Thus, testing should be started with voice or rock music. The multihandicapped youngster, like the young infant, will most
likely respond better to a complex rather than a simple stimuli (Hoversten and Moncur, 1969).

Stimuli should be presented initially at the loudest possible level so that the strongest response can be observed. As testing proceeds into more sessions, and as consistent responses to loud signals are determined, the intensity can be gradually reduced, and different types of signals can be used.

Noise makers which elicit the most consistent responses from a particular youngster should be taken along when the child goes to the audiologist for formal testing. Also, the parent, professional, or child-care worker should accompany the child to testing. They are perhaps the only individuals who can interpret response behavior for the audiologist.

Once a response has been elicited, the use of a tangible reinforcer might be considered. Suitable reinforcers are difficult to find for the multihandicapped youngster. The most frequent reinforcement is food such as candy, cereal, cookies, crackers, and so forth. If tangible reinforcers are not appropriate, another type of reinforcement might be more successful. Often, hugging the child, stroking his or her arm, rubbing his or her stomach, or patting his or her head are helpful. When a person works with a child for a long period of time, he or she becomes well acquainted with the child and is able to determine the most effective reinforcement.

Response Behaviors

In terms of response behaviors, what should be observed? The various forms of response are listed in Table 4 by developmental hierarchy. Generally, the lowest developmental response is that of the startle, which consists of a jumping or a quick tensing of the body upon presentation of a loud sound. The startle response can be elicited in normal hearing infants and adults when speech is presented at a moderately loud level (approximately 65 to 75 db hearing level). With the multihandicapped youngster, the absence of a startle response should not be construed to mean that the child has a severe hearing loss. Often the multihandicapped youngster does not have a startle response but does respond to signals presented at less intense levels. On the other hand, the presence of a startle response often suggests essentially normal hearing. Frequently, the startle response may be the only response that can be consistently observed.

A cessation of or an increase in baseline activity should be looked for at softer intensity levels (and a higher developmental level). These responses, which are often difficult to observe, may be represented by only a slight change in facial expression or general body movement. At a higher developmental level, one should look for a localization of the sound source; for example, can the youngster appropriately and quickly turn toward the source of the sound? One should be able to observe cessation of activity, increase in activity, and localization of activity when signals are presented at extremely low-intensity levels. Ultimately, the desire is to find the softest intensity which will elicit a consistent response. This level is referred to as the child's threshold of hearing or his or her hearing level. Further along the developmental scale is the child's ability to discriminate between noise makers and speech sounds.

In addition to observing the type of response, one should also note the manner in which the response was made. Was the latency between signal presentation and response short or long? Generally, a response to a loud or moderately loud signal should be observed within two seconds following initiation of the signal. How strong was the response? Did the child move slightly or was there a paroxysmal response? Was habituation present? Usually, when normal children are presented with a signal many times, they cease to respond. With the multiply handicapped, however, little habituation is noted.

All of the above information should be documented at the time of each test session on a form similar to that presented in Table 5. If possible, the form should be used during the initial session and then only when changes are observed in response behavior.
<table>
<thead>
<tr>
<th>Type of signal (specify)</th>
<th>Intensity</th>
<th>Type of response</th>
<th>Strength of response</th>
<th>Consistency of response</th>
<th>Response latency</th>
<th>Response habituation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time of day</th>
<th>Environmental conditions</th>
<th>Child's state</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - Early morning</td>
<td></td>
<td>0 - Sleepy</td>
</tr>
<tr>
<td>(8 to 10 a.m.)</td>
<td></td>
<td>1 - Subdued</td>
</tr>
<tr>
<td>1 - Late morning</td>
<td></td>
<td>2 - Quietly alert</td>
</tr>
<tr>
<td>(10 to 12 a.m.)</td>
<td></td>
<td>3 - Actively alert</td>
</tr>
<tr>
<td>2 - Early afternoon</td>
<td></td>
<td>4 - Hyperactive</td>
</tr>
<tr>
<td>(1 to 2 p.m.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 - Late afternoon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2 to 4 p.m.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 - Early evening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4 to 6 p.m.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 - Late evening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6 to 8 p.m.)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intensity of signal</th>
<th>Type of response</th>
<th>Strength of response</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - Very soft (&lt; 20 db)</td>
<td>0 - None</td>
<td>0 - None</td>
</tr>
<tr>
<td>1 - Soft (20-40 db)</td>
<td>1 - Startle</td>
<td>1 - Questionable</td>
</tr>
<tr>
<td>2 - Average (40-60 db)</td>
<td>2 - Cessation of act</td>
<td>2 - Present (slight)</td>
</tr>
<tr>
<td>3 - Loud (60-80 db)</td>
<td>3 - Initiation of act</td>
<td>3 - Present (strong)</td>
</tr>
<tr>
<td>4 - Very loud (&gt; 80 db)</td>
<td>4 - Localization</td>
<td>4 - Paroxysmal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consistency of response</th>
<th>Response latency</th>
<th>Response habituation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - Poor</td>
<td>0 - &gt; 5 sec</td>
<td>0 - None</td>
</tr>
<tr>
<td>1 - Fair</td>
<td>1 - 3-4 sec</td>
<td>1 - Slight</td>
</tr>
<tr>
<td>2 - Average</td>
<td>2 - 1-2 sec</td>
<td>2 - Average</td>
</tr>
<tr>
<td>3 - Good</td>
<td>3 - &lt; 1 sec</td>
<td>3 - Moderate</td>
</tr>
<tr>
<td>4 - Excellent</td>
<td></td>
<td>4 - Great</td>
</tr>
</tbody>
</table>
Table 6
Summary Data Sheet of Auditory Responsiveness

<table>
<thead>
<tr>
<th>Child's Name:</th>
<th>Period: Weekly _____ Monthly _____ Yearly _____</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dates spanned:</td>
<td>to</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Period number</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. No response to sound</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Startle response to sound</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Cessation or initiation of activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Localizes sound source</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Responds to tone of voice; for example, stops to command “No!” or smiles to friendly voice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Attends to patterned sounds</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Discriminates between noise makers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Repeats rhythmic sequences</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Attends to and responds to familiar words; for example, name, “Hi!”, “bye-bye”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Follows simple commands with gesture; for example, “sit down” and “give me ball”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Follows simple commands without gesture</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Able to point to objects, parts of body, articles of clothing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Understands simple directions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Understands big and little; color words</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Understands: in, behind, in front of</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Can label objects by verbal description; for example, “show me where you sleep.” “Where are the children eating?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Such daily documentation should be entered into the summary form (Table 6) adapted from Collins and Rudolph (1975) and Stillman (1974). When such a form is used, the youngster's developmental progress can be charted over a period of weeks or months. If done on a weekly basis, the appropriate items are checked over a period of six weeks. The same summary could also be made on a monthly or yearly basis. If compiled on a yearly basis, progress could be charted over a six-year period.

**Formal Audiological Evaluation**

In any formal evaluation, the audiologist should attempt to ascertain the hearing status of the individual by answering the items listed in Table 7.

**Table 7**

Information to Be Gathered from the Audiologic Evaluation

1. Extent of hearing impairment
   a. Degree of loss in decibels
   b. Significance of hearing impairment to:
      (1) Speech and language development
      (2) Psychosocial development
      (3) Educational development

2. Difference in hearing between the two ears

3. Frequency characteristics of hearing loss

4. Type of hearing impairment
   a. Peripheral
      (1) Conductive
      (2) Sensorineural
      (3) Mixed
   b. Brain stem
   c. Cortical

5. Ability to discriminate and process speech

6. Ability to adapt to and utilize amplification

The basic intent of any testing is to define the extent of the hearing impairment, not only in terms of the decibel level but also in terms of the significance of the hearing loss to speech and language development, psychosocial development, and educational achievement.

For recommendation of appropriate amplification, the audiologist needs to know if there is any significant difference in hearing acuity between the two ears and the frequency characteristics of the hearing loss. In terms of potential medical management, he or she needs to know if the hearing loss is primarily conductive or sensorineural in nature, because most middle ear problems are amenable to medical and/or surgical treatment. Once the hearing impairment has been identified, the child's potential to adapt to and use amplification must be determined.

**Behavioral Testing**

A listing of behavioral tests which can be administered according to developmental level is presented in Table 8. Traditional behavioral techniques, such as pure tone audiometry used with older youngsters, have not been successfully applied to the evaluation of the multi-handicapped deaf-blind youngster (Barr, 1955; Goetzinger, 1976; Sweitzer, 1977). Test personnel are just beginning to obtain reliable conditioned responses to pure tones with youngsters twelve to fifteen years old; that is, dropping beads into a box in response to sound. Other clinicians have experienced similar difficulty in obtaining reliable and valid results with the multi-handicapped (Calvert, 1972; Tweedie, 1972; McClatchie, 1973, and Tait, 1977).

**Table 8**

Outline of Formal Test Procedures

1. Behavioral
   a. Behavioral observation audiometry (BOA)
   b. Conditioned orientation reflex audiometry (COR)
   c. Tangible reinforcement operant conditioning audiometry (TROCA)
   d. Play audiometry
   e. Speech audiometry

2. Objective
   a. Tympanometry
   b. Acoustic reflex
   c. Cortical evoked response audiometry
   d. Brain-stem evoked response audiometry
   e. Electrocochleography
   f. Electrodermal audiometry

Behavioral observation audiometry (BOA) has been the best technique for determining the ability of the multi-handicapped child to respond to and to use auditory information (Hoversten and Moncur, 1969; Thompson and Weber, 1974). This technique is commonly used with infants and is extremely useful when testing retarded or emotionally disturbed youngsters. The only difference between testing on an informal basis and the application of BOA by the audiologist is that the audiologist can present stimuli of known spectral characteristics under controlled environmental con-
ditions. Signals are presented with loudspeakers in a sound-treated room, as shown in Figure 4. At the Joseph P. Kennedy, Jr., Memorial Hospital for Children, speakers are located at angles of 135 and 315 degrees from the front of the child. Sounds are presented to each speaker on a random basis as the child is observed for any changes in his or her behavior. Thus, an attempt can be made to define not only the degree and the frequency characteristics of the hearing loss but also any differences in hearing acuity between the two ears. Earphones rather than loudspeakers can be used if they can be tolerated by the child.

When the blind youngster has limited vision, the residual vision, particularly light perception, can be used to advantage in conditioned orientation reflex (COR) audiometry (Suzuki and Ogiba, 1961; Sweitzer, 1977). The same physical arrangement is used as for BOA, except that with COR bright lights are positioned above each loudspeaker (Figure 4). In testing, the child is conditioned initially to respond to the simultaneous presentation of sound and light from each of the loudspeakers. Once conditioning has been firmly established, the light is removed and sound alone is presented. If an appropriate response is observed—correct and quick localization of the sound source—the light is presented as a reward. The procedure has had minimal success, but, because of the fact that the light tends to increase the "blindisms" of the deaf-blind and multihandicapped youngster, the procedure has not been totally successful (Tait, 1977).

Some success has been achieved in using operant behavioral techniques with tangible reinforcement operant conditioning audiometry (TROCA) (Lloyd, Spradlin, and Reid, 1968; Fulton and Lloyd, 1969; Calvert, 1972; and Tait, 1977). Conditioning audiometry has been developed into a very sophisticated and automated procedure with strict control over stimulus characteristics, reward schedule, and patient response pattern. In essence, TROCA is used on an informal basis any time a youngster is rewarded for appropriate response behavior with a tangible reinforcement.

Objective Test Procedures

Two objective test procedures which have received acclaim from audiologists are as follows:

Tympanometry. This objective test procedure requires no active participation on the part of the child. The procedure assesses eardrum mobility and thus can be used to detect the presence of middle ear abnormalities; that is, fluid (Brooks, 1968; Jerger, 1970; Bashore, 1976; Feldman, 1977). Although it is an extremely useful procedure in terms of differential diagnosis, tympanometry is not an easy assessment to complete. A probe has to

Fig. 4. Test room conditions for BOA and COR audiometry
be placed in the youngster’s ear canal. The procedure is not painful, but it may be uncomfortable and may upset an already hyperkinetic, irritable, and generally difficult-to-control youngster. Under extreme circumstances the use of sedation with medical management may be required. However, even the use of sedation with the multihandicapped youngster may not prove to be extremely successful.

Tracings which are usually obtained with this procedure are shown in Figure 5. The normal tracing should exhibit a peak, or point of maximum eardrum mobility, at 0 mm H₂O, indicating the normal state of equal pressure in the atmosphere and the middle ear, which also contains air. Tracing number 1 is normal. Tracing number 2 exhibits a condition of otosclerosis commonly found in adults when there is reduced mobility of the ossicular chain. Although the peak occurs at 0 mm H₂O, the eardrum is not as compliant as in the normal. Tracing number 3 exhibits normal eardrum mobility, but the mobility is not present until a negative pressure has been applied against the eardrum. This condition is usually the first stage of a middle ear effusion, and otoscopic examination would show that the eardrum is retracted. If the condition in tracing number 3 persists, fluid may develop in the middle ear, resulting in tracing number 4, which shows no eardrum mobility.

When only negative pressure is evident, as in tracing number 3, little hearing loss is usually present. Once fluid develops in the middle ear, however, a conductive hearing loss of 30 to 40 db is not uncommon. This conductive hearing loss is then superimposed upon any existing sensorineural hearing loss until the child has had appropriate medical and/or surgical treatment.

The importance of tympanometry in the assessment of the multihandicapped youngster cannot be overemphasized. It is a waste of time to evaluate an already difficult-to-test child when there is evidence of middle ear involvement. Therefore, tympanometry is the first part of a number of tests conducted on any youngster. If middle ear fluid is evident, the child can be referred for medical management, with further audiological testing being postponed until the middle ear condition has been resolved.

Acoustic reflex measurement. Since tympanometry assesses eardrum mobility, the test procedure in essence is used to determine the stiffness of the eardrum. The middle ear has two muscles—the tensor tympani and the stapedius—which, upon contraction, stiffen the eardrum. In the individual with normal hearing, the muscles contract upon presentation of a loud sound. This contraction is referred to as the acoustic reflex. By using the same instrumentation used for tympanometry, the audiologist can present loud sounds to a youngster and watch for the presence of acoustic reflex. The intensity required to elicit the reflex can be compared with that required by the normal individual, and by applying a formula, a comparatively accurate prediction can be made of the patient’s hearing loss (Jerger, 1974).

With a very objective test procedure, information may be obtained relative to the integrity of the peripheral (middle and inner ear) auditory system. Thus, such a test will indicate whether or not there is a hearing loss. More importantly, information is needed concerning how the child uses the sound that he or she hears in adapting to his or her environment. Objective tests do not yield such information; therefore, observation of the child’s auditory responsiveness is the most important tool for predicting the appropriate educational management.

Many youngsters have perfectly normal peripheral hearing but have considerable difficulty understanding and processing auditory information. These youngsters are often labeled as having auditory perceptual problems (Katz and Illmer, 1972; Topp, 1977). Such problems are not uncommon in the deaf-blind and multihandicapped population and are particularly evident when the etiology is maternal rubella (Ames and others, 1970). The auditory perceptual problems may be so great that the youngster may not be able to interpret the meaning of his or her name, or even recognize the importance of various auditory warning signals such as a car horn or a siren. Only through observation of auditory behavior can such difficulties be detected.
Fig. 6. Tampanograms

1) Normal
2) Otosclerosis
3) Eustachian tube dysfunction
4) Serous otitis
References


To understand human vision and the imperfections that exist within the vision system, one must have some understanding of basic ocular anatomy and physiology. The eye is an image-catching device. No matter how much this apparatus may vary from one kind of animal to another kind of animal, vision is always the same in one fundamental respect. The process begins with light entering the eye, bringing with it the information picked up in touching or passing through the objects in its path. These light patterns travel through the various parts of the eye until an image is cast upon the retina at the back of the globe of the eye.

**Eye Structure and Physiology**

Getting a clear, intact image to the retina is a rather complex process. First, the amount of light entering the eye must be controlled. If there is too much light, the image will glare; if there is too little light, the image will be indistinct. Next, the image must be focused sharply on the retina. In the human eye the tasks of controlling and focusing light are performed by a delicately engineered system. The coordination and ability of this system to adapt to various conditions make other sophisticated optical systems appear to be relatively simple in design.

**Cornea**

Located at the front of the eye is the cornea, a transparent tissue rising from the outermost layer of the globe of the eye. The cornea bends the light and is, therefore, part of the focusing mechanism. About 70 percent of the light that enters the eye is bent or focused by the cornea. Imperfections in the shape of the cornea caused by disease, injury, or developmental anomalies can sharply reduce both the quantity and quality of a person's vision.

**Aqueous Humor**

Behind the cornea is a clear fluid called the aqueous humor, which is constantly being replenished by an intricate circulation system within the anterior chamber of the eye. The pressure of the aqueous humor from behind the cornea helps maintain the shape of the cornea and plays a part in focusing the light rays that enter the eye.

**Iris**

The posterior wall of the anterior chamber is composed of the colored iris with its hole, the pupil, which is almost directly in line with the center of the cornea. The iris governs the amount of light that enters the eye by increasing or decreasing the size of the pupillary opening.

After light has passed through the cornea, aqueous humor, and pupil, it goes through the lens, which does the fine focusing for near or far viewing.

**Globe**

Finally, the light proceeds through a jelly-like substance called the vitreous humor in the posterior chamber of the eye. This substance helps maintain the shape of the globe of the eye and bends or focuses the light rays a small degree before they reach the retina.

The globe of the eye is made up of three distinct layers. The outermost layer is called the sclera, which is characterized by its elasticity, opaqueness, and fibrous tough consistency. The sclera serves to maintain the shape of the eye and helps hold all of the eye's structures in proper relationship with each other.

The choroid, the middle layer of tissue, is made up of nearly all the vessels which supply the eye with blood. The choroidal layer is continuous with the ciliary body, which houses the muscular apparatus. The muscular apparatus controls the focusing of the crystalline lens by increasing or decreasing the tension on the zonular fibers, which in turn connect the lens capsule to the surrounding ciliary body and holds the lens in its proper position. The choroidal layer is also continuous...
with the iris which controls the amount of light entering the eye.

The innermost layer is the retina, which is actually two separate layers. The retinal pigment epithelium lies firmly attached to the choroid and reflects light into the retinal visual receptor layer, which has its receptor cells facing outward in a tead of inward. The three different types of receptor cells are (1) cones which are used for the most acute visual needs and color perception; (2) rods which are used for night vision and peripheral vision; and (3) pupillary receptors which control the dilation and constriction of the pupil by the amount of light falling on their sensitive heads.

The light rays, which are mechanically focused on the retina by the cornea and lens, are transformed into electrical signals and sent to the occipital cortex of the brain. The retinal surface is marred by veins and arteries lying on top of the retinal fibers and receptors and is marked with areas of greater or lesser sensitivity. Vision is acute only when the objects are seen straight on; their images fall on the fovea, a tiny pit in the center of a slight depression called the macula. The spot on the retina where the optic nerve fibers leave the eye is blind because it has no light-responsive cells. These fibers carry the signals collected from the receptors of the retina to the brain for translation into what is known as sight.

The foregoing review of the structure and basic physiology of the healthy eye is intended to provide a better understanding and appreciation of some of the anomalies and defects of the eye caused by injury and disease. The signs, symptoms, and problems arising from these visual anomalies, as well as the means of providing afflicted persons with improved vision, must be understood by those who come into contact with the visually handicapped. This information will ensure that visually impaired persons will be provided with the maximum of educational opportunities, with consideration given for the severity and type of their specific visual impairment.

Maternal Rubella Syndrome

The maternal rubella syndrome is one of the most devastating afflictions which causes both physical and visual anomalies. Universally, rubella is recognized as an acute, self-limited, exanthematosus disease of children and young adults, which is caused by an RNA virus of the arbovirus group. The disease is most often diagnosed when it occurs in epidemics, but sporadic cases occur frequently. One of the most tragic effects of rubella is its ability to cause congenital abnormalities when contracted by the mother during the first trimester of her pregnancy. In general, the earlier in the course of pregnancy the illness is contracted the more likely the fetus is to be affected and the more severe the manifestations. The viral effect, transferred to the fetus by way of the placenta, appears to retard the replication of the fetal cells, thereby delaying normal organogenesis of early gestation.

Congenital Abnormalities

The congenital abnormalities caused by maternal rubella are usually bilateral because of the systemic nature of the disease. In addition to visual defects, rubella causes congenital deafness, which may be of varying degrees of severity, depending on the amount of destruction to the organ of corti. Cardiovascular anomalies such as patent ductus arteriosus, ventricular septal defects, or pulmonary stenosis are also commonly manifested.

In many cases there is evidence of microcephaly and mental retardation ranging from minimal to profound. There are also disturbances in somatic (wall of the body) growth and abnormalities of the general physical developmental process. Psychomotor retardation is usually apparent from the very evident lack of development of perceptual and fine-motor skills. The rubella child may also be born with any one of a great number of acute infections, such as hepatitis, myocarditis, encephalitis, or leptomenigitis. The newborn infant generally displays a low birth weight, leaving it in a very weakened condition and susceptible to numerous infectious agents. Pathological studies indicate that the rubella infant's organs contain a subnormal number of cells and that there is a significant disturbance in bone growth. From all the possible complications that may be associated with maternal rubella, one can readily see why there is a very high rate of early natural abortions and a high rate of fetal fatalities (stillbirth).

Ocular Defects

The ocular defects associated with maternal rubella are numerous and often so severe that they are totally disabling. The most commonly recognized ocular anomaly associated with rubella is congenital cataracts, which are usually bilateral, but can be unilateral. They are also generally nuclear (affecting the central portion of the lens), although they may involve the whole lenticular body. The cataractous opacity is: pearl color and very dense in nature, preventing the normal passage of light through the ocular media to the retina.
Surgical treatment to remove the cataracts is almost always necessary. Many times surgery is complicated by the child’s poor physical health and congenitally small eye and cornea, which are referred to as microphthalmia and microcornea, respectively.

Disruption of the retinal pigment epithelium (rubella retinitis) is a frequent ocular feature of rubella syndrome, which is present in 25 to 50 percent of the reported cases. This condition is usually bilateral and is evidenced by retinal pigmentary deposits varying from fine, powdery, sprinkled, or granular shapes to more discrete shapes. The pigmentary changes are limited to the posterior pole of the eye, giving the fundus a “salt and pepper” appearance, with the deposits being of greater density and slightly larger size in the macular area. However, the characteristic poor vision noted in the rubella child is generally not due to the retinal pigmentary changes, but rather due to other related ocular defects, such as congenital cataracts, poor macular development, optic nerve atrophy, and microphthalmia. Glaucoma is often present and is thought to be caused by the incomplete formation of the anterior angle. Diagnosis of rubella glaucoma is very difficult, and management of the disease is many times impossible. The vague and misleading clues often lead to a misdiagnosis of infantile glaucoma and the performance of unnecessary surgery.

Corneal clouding is sometimes evident by the absence of Descemet’s membrane and by endothelial cell disruption in the central cornea. The integrity of the corneal endothelium and Descemet’s membrane is essential for the maintenance of the delicate water or fluid pump mechanism which regulates and controls the crystal clarity and transparency of the corneal cellular structure. Other ocular conditions which may be associated with maternal rubella are (1) strabismus, which is caused by the lack of development of fusional control: (2) nystagmus, which is due to the failure of formation of the fixation reflex: (3) iridocyclitis (anterior uveitis): (4) viral dacryoadenitis, which is an inflammation of the lacrimal gland: (5) nasolacrimal duct obstruction, which causes epiphora: (6) miotic pupil, which dilates poorly and is caused by iris hypoplasia (complete or partial absence of the iris dilator muscle): (7) necrosis of the ciliary body; and (8) optic nerve fiber damage and extremely high refractive errors.

Ocular Manifestations

Ocular manifestations related to maternal rubella are the result of a virus invasion of the ocular tissues. Surgery for cataract extraction, glaucoma, and so forth can be followed by severe complications from the live virus that remains in the body tissues for extremely long periods of time after birth. Live rubella virus has been recovered from the throat of a child 18 months after birth. The virus has also been detected in the urine 29 years following the rubella infection. Surgical procedures can release the residual live virus into the eye and its related structures and, consequently, excite severe inflammation. The existence of active rubella virus within the ocular tissues is the reason for the chronically progressive ocular damage and degeneration following birth in the lens, cornea, iris, retina, and other related ocular tissues.

Physical and Emotional Limitations

The initial clinical picture of a deaf-blind child is a tragic one. Usually, the child is severely mentally retarded with very limited communication skills, which may vary from the possession of some signing skills to absolutely no communication skills. This child undoubtedly has severe emotional problems created from the lack of sensory input, such as limited physical, emotional, and social experiences, and from the lack of a means for expressing himself or herself. These physical and emotional limitations manifest themselves in very erratic behavior, ranging from mild restlessness to violent, overt reactions.

To complicate the clinical situation even more, the deaf-blind child usually has developed a fear, distrust, or dislike for doctors, nurses, and clinical environments of any type because of previous experiences with health care professionals, clinics, hospitals, and so forth, which resulted in physical or emotional pain, separation from parents, and associated loss of security and contentment. High refractive errors are also characteristic of the deaf-blind child. High myopia and astigmatism may result from the presence of microphthalmia. A high hyperopic refractive error is prevalent with the child who is aphakic secondary to cataract surgery. Uncorrected aphakia renders the child “out of focus” for all viewing distances, while the uncorrected myopia may aid the child in seeing up close by providing a magnification effect of objects of regard that are held within the focal length of the myopic eye.

All of the above factors make it difficult, and many times impossible, for the deaf-blind child to be visually examined under normal, structured, clinical conditions in which dependence on subjective response from the patient is necessary for a definitive evaluation. The clinician’s lack of control
of the child’s fixation and focusing mechanisms and the child’s limited or nonexistent ability to follow even basic instructions forces almost total reliance on objective findings and impressions to perform a visual examination.

Visual Examination

A logical question to ask at this time is can a deaf-blind child be successfully examined and treated by visual means? I feel the answer to this question is an unequivocal yes. Although the quantity of information on this subject is limited, it does not restrict successful treatment. The objective data that can be obtained is generally of good quality and accuracy.

A modified clinical approach must be used to gather valid and reliable data. The most important rule is to keep the child as relaxed, calm, and undisturbed as possible. The child should not be examined in a structured clinical environment. He or she should be in his or her own familiar environment. The examiner should wear casual, mute clothing so that he or she is not readily identifiable. The child should gradually become thoroughly familiar with the examiner through touch, smell, and so forth. The sense of touch and the security drawn from physical contact is probably the strongest sensory stimulation the deaf-blind child has, so the examiner must use it to the fullest degree. The relationship should not be rushed. The examiner may not be able to examine the child on the first or second exposure. He or she must create a situation that is comfortable for the child so that, when he or she is able to evaluate the child, the findings obtained will be valid.

Once the examiner has determined that the child will be receptive to an examination procedure, one of the best places to perform it is on the floor on a comfortable rug. This procedure allows the examiner to roll about and play with the child and to maintain constant physical contact during the evaluation. The examiner uses the deaf-blind child’s characteristic fascination with light to the best advantage during the procedure. Some of the assessment procedures that can be used in this modified testing situation are as follows:

1. **External examination** This procedure is a general external screening for pathologic and congenital or developmental abnormalities. It should include a rough cover test to determine the presence or absence of binocularity, using a penlight for a fixation target and the fingers to alternately occlude the child’s eyes. If strabismus exists, measurement of the angle of deviation is done by using a prism bar, penlight, and finger occlusion. Extraocular muscle motility skills are observed for such things as tracking skills, fixation reflexes, and convergence ability. A gross measurement of the visual fields can be made by using two penlights, one for fixation and one to localize and identify within the field of vision. A second person (teacher, parent, and so forth) is helpful at times in the visual field determination.

2. **Internal examination**—An ophthalmoscope is used in this procedure to determine the internal ocular physical health and to assess structural damage. The magnitude and speed of the direct, indirect, and consensual pupillary reflexes are noted.

3. **Retinoscopy**—A battery-powered retinoscope, a lens tree, and individual trial lenses are used to neutralize the optics of the child’s eye to measure objectively the refractive status and determine the need for a spectacle correction.

4. **Visual acuity**—Clinical visual acuity scores are determined as closely as possible, even though raw visual acuity scores are not very meaningful, other than for labeling and classifying the deaf-blind child for legal and agency identification. The doctor should be much more interested in determining visual functioning ability, which can differ greatly from impressions derived from a raw clinical acuity score and, in some cases, has little or no correlation.

Visual functioning ability is best determined by observing the child functioning in both familiar and strange surroundings and by noting carefully the situations in which the child used visually discriminated clues to make judgments. Further information can be obtained by carefully and systematically questioning a teacher, parent, or any other person who has an excessive amount of contact with the child.

The teacher, parent, or houseparent can be trained to be an expert observer in determining the functional visual acuity level. The visual acuity of deaf-blind children who are functioning at higher levels of performance can be determined by using symbol matching and recognition techniques with familiar object-type symbols or geometrical shapes. Visual functioning ability will be dealt with in greater detail later in this paper.

**Optical Corrections**

Spectacles are essential in the treatment program of almost all rubella children, with more
cated, low-vision appliances being used with children at the higher developmental levels. The classical optical problem with the deaf-blind child is surgical aphakia. This type of refractive error must be corrected with relatively high plus powered spectacle lenses, which compensate for the exceptionally high hyperopia. The spectacle correction is commonly referred to as cataract glasses, which correct the distance refractive error from approximately 12 to 18 feet from the child’s facial plane to infinity. Refractive correction for infinity is not an important factor for most deaf-blind children, because their visual world remains fairly close to their immediate physical location. For this reason overcorrection of the distance refractive error is a fairly common practice. Theoretically, this correction provides better vision at more intermediate viewing ranges; therefore, the deaf-blind child should have more functional vision.

I believe that a multifocal lens should be prescribed in almost all cases, even when one is uncertain of the amount of benefit that will be derived from the bifocal segment. One should not assume that a child cannot benefit from a bifocal addition until it is given a fair trial. The child’s performance with the multifocal segment should be closely observed during this time. I prefer to use relatively high-powered bifocal segments with deaf-blind children, usually in the range of +4.00 to +6.00 dioptr additions. The justification for using a higher powered bifocal addition is twofold. First, the deaf-blind child’s customary working or viewing distance is very short and close to his or her facial plane because of severe visual impairment; therefore, the higher powered segment allows a clear focus at this near viewing range. Secondly, a phenomenon referred to as distance magnification takes place as one holds an object of regard closer to one’s eyes. For example, an object moved from a viewing distance of 10 inches to one of 5 inches is magnified two times. A higher powered bifocal segment allows the child to focus with clarity at nearer viewing ranges so that he or she may take advantage of distance magnification. Ideally, the bifocal segment should be set high in the spectacle lens so that the top of the segment coincides with or is just slightly lower than the inferior pupillary margin. The extended height and width of the bifocal facilitates its use. When the child lowers the level of his or her fixation even the slightest for near viewing, the eyes are automatically aligned through the bifocal segment. As the child is rewarded with larger and clearer images through the bifocal segment, he or she will learn to use the segment for near viewing, through self-training techniques. Any resistance by the deaf-blind child to wearing his or her spectacles is usually not due to an incorrect lens prescription but most often due to discomfort created by improperly fitting spectacle frames. Because of the extreme weight of the high-powered lens prescribed for deaf-blind children, proper frame fitting and alignment becomes a very important factor in the child’s care and treatment program.

Visual Aids

Modifications of the basic spectacle correction, as described above, and slightly more sophisticated low-vision aids can be applied to the treatment of deaf-blind children who are functioning at higher levels of intellectual and psychomotor development. These visual aids can be categorized into two major groups: (1) aids used for near viewing purposes; and (2) aids used for distant viewing purposes.

Aids for Near Viewing

Those aids used for near viewing purposes are as follows:
1. Modified bifocal technique. A bifocal strength one-half the desired power is prescribed, and an auxiliary Fresnel “stick-on” lens of the same power is applied to the back surface of the lens. The stick-on lens is cut in such a way so that it not only covers the bifocal segment but also extends slightly above it to provide a trifocal lens effect. The power of the bifocal lens and the Fresnel lens is additive, giving the bifocal the strength originally desired. The power in the extended trifocal portion provides an intermediate focal point which is functional between infinity, or the far point of clear vision through the upper portion, and the near focal point through the bifocal. This effectively increases the range of clear, usable vision of the aphakic eye through the spectacle lens and hopefully provides for improved visual functioning at intermediate viewing distances.
2. Hand magnifiers. Hand-held magnifiers of various types and powers, both nonilluminated and self-illuminated, are used in conjunction with the child's spectacle correction.
3. Stand magnifiers. Both nonilluminated and self-illuminated stand magnifiers are used in conjunction with the child's spectacle correction. This type of magnifier has the advantage of being automatically in focus when firmly
sitting on the reading page and, therefore, is more successful when used with children who have poor fine-motor development and who cannot successfully focus a hand magnifier.

4. Microscopic lens systems. Occasionally, a microscopic system of sufficient strength to compensate for both the distance refractive error and the near working distance can be used for near viewing and reading purposes. This type of aid can only be used for a child who is on a higher developmental plane and who has the motivation to use his or her near vision for more advanced academic purposes.

5. Electronic magnifier. Infrequently, a deaf-blind child may be trained to use an electronic magnification system. This incidence is rare, but the possibility must be explored when it seems appropriate.

Aids for Distant Viewing

Low vision aids sometimes found useful with deaf-blind children for distance viewing are as follows:

1. Hand-held telescopes. A monocular hand-held telescope for distant spotting, and so forth, can be used when the child possesses the intellect and fine-motor coordination necessary for functioning.

2. +3.00 biconvex lens. A simple +3.00 biconvex lens mounted in a plastic carrier with a convenient handle can be used to sight through at distant objects without the child's aphakic spectacles in place. By using the refractive status of the uncorrected aphakic eye as the eyepiece of the telescope, the +3.00 lens simulates the objective lens of the telescope by being held at the precise distance from the eye which will complete the optics of the telescopic system. This aid has the advantages of being easy to carry, economical to purchase, and, generally, handy to use.

3. Biopic telescope. A biopic telescopic system is a fixed-focus telescope mounted into the upper portion of the spectacle lens. It is functionally used for distant spotting by rotating the head downward and aligning the eye through the telescope with the object of regard. This type of aid is used only in rare cases in which there is sufficient physical and mental aptitude for proper performance.

Obviously, the success and usefulness achieved by a deaf-blind child with any of the previously described aids will depend on the (1) severity of the visual impairment; (2) intelligence factors; (3) psychological attitude; (4) motivation; and (5) motor development as it relates to handling and controlling the low-vision appliances. The higher the developmental and maturation level, the greater the complexity of aid that can be used. The child's progress with the use of any visual aid must be closely observed and monitored for its effect on visual functioning ability, both academically and socially. The child must be continually encouraged to use his residual vision, while reinforcing this function with sensory input from the other sense modalities.

Visual Functioning

After all the proper clinical visual care has been provided, the child still must be taught to function visually. Traditionally, educational philosophy concerning the visually impaired dealt with sight-saving or sight conservation programs and techniques. Often the visually impaired child was educated as though he or she was totally blind, learning braille and developing his or her tactile sense far more than his or her visual sense. Within the last 10 to 15 years, the philosophy on educating the deaf-blind has shifted radically. This shift came about when it was found that the use of residual sight is not physically harmful and does not lead to further visual degeneration, as it was once believed. Further, it was also realized that distance visual acuity does not reflect near visual acuity, and considerable visual functioning ability can be developed by teaching the child to use his or her near vision. When one uses visual stimulation techniques of various designs, a positive change in visual development and performance can be affected almost 100 percent of the time. The use of vision, just as with the normal visual development process, is a learned function and can be taught and trained even in visually handicapped children.

Since greater emphasis has been placed on the visual development of visually impaired children, it has been found that many deaf-blind children function on merely a sensorimotor level only rather than on a perceptual level. These children rarely respond to outside stimuli and fail to develop any perceptual interpretations and impressions concerning their visual world. Even when deaf-blind children are found to be functioning and responding on a perceptual level, physical handicaps other than visual impairment make it impossible for them to plug into conventional visually stimulating programs. Their hearing loss has the effect of further compounding their sensory input problem. These children do not possess an ade-
quate symbol system for communication purposes and, therefore, they have no way of recording or registering the perceptual impressions gathered from their environment. Special communication techniques must be provided so that language skills can be developed. In the rubella child, additional learning disabilities and unacceptable behavior patterns are attributed to the associated brain damage. Because these children receive very little sensory input and have limited means of self-expression, they accumulate large amounts of internal energy, frustration, and stress, which results in a self-stimulating type behavior that provides a release for this energy. This self-stimulating behavior may be observed as the characteristic flipping against a bright light source, rocking, and so forth.

The proper and accurate assessment of the deaf-blind child’s visual functioning ability is exceedingly crucial to all of his or her educational and social development programs. A comprehensive determination of the child’s level of visual functioning involves evaluation in the prime performance areas of visual sensation, visual-motor function, and visual perception. Those persons who contribute essential data to such an assessment are vision care specialists, including ophthalmologists, optometrists, psychologists, social workers, and teachers. From a pathological standpoint, the cause, treatment, and prognosis of a particular eye condition is the responsibility of the ophthalmologist. Once physical restoration of the visual organ has been maximally attained, the optometrist should be concerned with both the sensory and visual-motor skills. Visual-perceptual development is generally guided by the psychologist. The teacher's responsibility is to evaluate all of the testing results and then properly and effectively apply them to the child’s learning experience. Because the teacher must rely heavily on reports from other professionals, it is essential that these reports be complete and that they contain useful information. Unfortunately, some vision care specialists view the visually impaired, especially deaf-blind children who are extremely hard to handle, as a threat to their professional security, their general peace of mind, and the continuity of their professional practice. Since most people’s eyes are correctable to near normal vision, very few professional offices are equipped to handle the low-vision patient. Because it is extremely time-consuming to examine a deaf-blind child, many are not properly evaluated, and consequently, inadequate data are provided to the teacher. Sometimes the teacher must formally request specific vision information from the doctor. Although the doctor does a thorough evaluation, many times he or she is not knowledgeable about the facts and information needed by the teacher. Efron and DuBoff (1975) have suggested that a structured questionnaire be presented to the doctor.

Assessing Visual Sensation

Assessment of visual sensation involves determining the child's reaction to a light stimulus. Reactions such as general awareness of the light and responses such as a change in activity and behavior are noted. Increased or decreased response to various colored light sources can provide further clues. Sometimes the light stimulus creates abnormal behavior such as flipping or flicking, head rolling, rocking, and other violent behavior patterns. These adverse reactions to the light stimulus can be used to determine optimal lighting standards for further evaluation procedures. Visual acuity testing should be informal and unstructured and conducted with objects familiar to the child.

Visual sensation response can be improved through training techniques. Since light commands the constant attention of the deaf-blind child, penlights, colored filters, mirrors, flashers, and so forth can be used to train visual awareness. The child must be taught to use the light stimulus in a positive or productive manner rather than for self-stimulation. The training of functional visual acuity may involve matching symbols, matching pictures, and using form boards. As acuity training proceeds, an attempt should be made to train at greater and greater viewing distances to expand the child’s functional visual world.

The quality of oculomotor and focusing skills and the ability to coordinate the visual process with other body parts constitute the efficiency of the child’s visual-motor skills. Proper and accurate evaluations of these skills are critical, because higher level visual skills such as visual perception depend on efficient oculomotor performance. When the child’s tracking ability is evaluated, he or she is encouraged to follow or track a moving penlight. This ability depends on the smoothness and accuracy of movement, as well as the child’s visual fixation reflexes, visual saccade, and convergence ability, and his or her ability to cross the midline. Accommodation or near focusing ability is determined not only in terms of maximum amplitude but also its flexibility, which many times is more important than the amplitude.
Attention must be given to the interrelationship between gross or skeletal motor coordination and fine-motor coordination. The child is requested to perform various hand-eye and fine visual-motor coordinative tasks, and his or her abilities are compared to norms for children at the same maturation level. Accurate and meaningful records are needed to properly assess future improvement of visual-motor skills that result from training. The developmental level of visual-motor skills is raised by teaching the child greater control of his or her oculomotor skills. In training visual-motor skills, it is extremely important to develop eye-contact skills, which are essential skills for good hand-eye coordination and visual perception, and most important for the development of socialization skills.

Body awareness is crucial to the deaf-blind child. He or she must be made aware that his or her body is both a whole structure and a conglomeration of parts that are finely tuned and synchronized to move the whole body structure through space. Large mirrors are useful in this phase of visual-motor training. The child must be taught to localize other objects in his or her visual world. Visual localizations are then reinforced by the sense of touch so that the child can determine the accuracy of his or her visual judgment.

Determination of visual perception skills is an evaluation of how much the child has gained and retained from his or her previous visual experiences. Visual information normally should be perceptually processed into usable data that can be retained in the visual memory for future use. The ability to do this, as was stated previously, depends on the quantity and quality of visual sensation and visual-motor skills. Assessment of the deaf-blind child’s level of visual perception is accomplished by observing how well the child knows the meaning and purpose of objects that are normally encountered in his or her daily routine; how well he or she discriminates size, shape, and color; the strength of his or her visual memory; his or her visual directionality and figure-ground skills; and his or her ability to duplicate visual stimuli presented to him or her.

Refinement of visual perceptual skills ensures that the child will gain greater benefit and meaning from what he or she sees. An attempt to develop greater accuracy of perception is accomplished by increasing the child’s awareness of differences in size, shape, color, density, and so forth. The rate of perception should also be increased, but not at the expense of the accuracy of perception. Figure-ground perceptual skills are strengthened by teaching the child to focus and isolate a particular object from within a complex and cluttered visual surround without letting the cluttered background mask or confuse the visual discrimination. Visual memory is improved many times by the use of sequence training techniques, such as duplicating the order of beads strung on a string or by sequencing coded pegs on a pegboard. Children who are functioning at higher levels may benefit from the use of more advanced materials such as the Michigan Tracking Program, Michigan Language Program, and various Frostig techniques.

The deaf-blind child is indeed a visually functioning person who needs the same visual skill development as a normal child. Since he or she does not have the opportunity to develop in a normal functional pattern, specialized techniques, care, and programming are required to assist him or her in achieving physical, mental, and social growth.

References


Multiple Handicaps: A Developmental Approach to Their Assessment

Vanja Holm, M.D.
Assistant Professor in Pediatrics
University of Washington School of Medicine, Seattle, Washington

The functional and behavioral characteristics of children with developmental disabilities are frequently given labels. Examples of such labels are deaf-blind and developmental disability. Like most labels used to describe handicapping conditions, they have an official definition with legal, service, and educational implications. These labels were created in recent years because most of the older labels (for example, mental retardation, hearing impairment, cerebral palsy, and visual impairment) were narrow in scope and did not account for the fact that most children with significant developmental deviations usually have more than one handicap. An overview of how biological and environmental determinants interact to result in functional deviations called handicaps is given in Figure 1.

**Biological Insults**

Biological insults known to adversely affect the human organism are related to genetic, toxic, infectious, and traumatic causes, and may occur before, during, or after birth. The effect of most such insults is both multifarious and variable. This fact is illustrated by the multitude of minor and major anomalies caused by chromosomal abnormalities. However, an individual with Down’s syndrome, for example, may have approximately one-quarter the anomalies known to be associated with this syndrome. Dominant inheritance is known for variability in penetrance; that is, a mildly affected parent may have a severely affected child. This can happen, for example, in the case of tuberous sclerosis. The effect of recessively inherited diseases on physical development is somewhat more predictable, but they share the frequency of multiple physical effects with other genetic diseases. The Laurence-Moon-Biedl syndrome is a good example. Intrauterine infection by cytomegalic inclusion disease virus (CID) might result in a normal fetus or one severely affected with sensorineural hearing loss, growth retardation, blindness, microcephaly, and so forth. The unpredictability of the eventual outcome from a difficult birth is well known. The adverse effects of postnatal insults are mainly related to brain damage. The notion of multifarious and variable effects on the human organism by single biological insults could be augmented by many examples.

In spite of the explosive growth of medical knowledge, it is a sobering fact that a precise medical diagnosis cannot be made for three-quarters of the children affected with developmental disabilities. However, these as yet undiagnosable conditions share with the better understood conditions the likelihood of a multiplicity of physical effects, and, as each new syndrome is better described, variability usually becomes apparent.

**Physical Abnormalities**

Most of the biological insults occur prenatally and result in physical abnormalities that are revealed as the child grows. Physical congenital anomalies are apparent at birth or shortly thereafter. But the physical effects on the brain depend on neurological maturation of the central nervous system (the brain and its pathways), which continues through childhood. Maturation is most rapid during the first few months of life, but significant abnormalities may not be recognizable for weeks.
or even months. The detection of some physical abnormalities, like damage to the cochlea (inner ear), require so much maturation of functional behavior that they might take years before they are recognizable.

Environmental Influences

As soon as the fetus leaves the womb, the molding of its personality or the shaping of its behavior is being influenced by the environment. Although the old nature versus nurture argument has subsided, no general agreement has been reached in regard to the relative significance of each. For the purpose of this treatise, with regard to developmental handicaps, the importance of environmental factors (training) relative to intrinsic factors (organic deficits) has been underestimated in the past, at least by the medical profession. Behavior modification techniques used to teach self-help skills to severely impaired individuals and neurodevelopmental therapy used to decrease the degree of disability due to spasticity are examples of the fact that even though the physical effects of a biological insult cannot be changed, environmental influences can modify the functional outcome.

Functional Deviations (Handicaps)

Observations of physical and behavioral deviations resulting from abnormal biological influences on development preceded the knowledge of their precise origin. Physical congenital anomalies are depicted on ancient sculptures, and blindness and deaf mutism are mentioned in biblical writings. Jean Itard wrote his famous and surprisingly modern description of the treatment of mental retardation, *The Wild Boy of Aveyron*, in 1801, and Little described spastic diplegia (a common form of cerebral palsy) in 1843. These and other handicaps will be defined later by using a developmental approach.

Visual Handicaps

In 1934 the American Medical Association adopted the following definition of legal blindness:

A person shall be considered blind whose central visual acuity does not exceed 20/200 in the better eye with correcting lenses, or whose visual acuity, if better than 20/200, has a limit of the central field of vision to such a degree that its widest diameter subtends an angle of no greater than 20 degrees.

This definition is still generally accepted. Partially sighted persons are those persons with vision between 20/70 and 20/200.

Visual tracking, vertically and horizontally, is present at a developmental age of three months. Sometimes it is possible to predict with 100 percent accuracy before that age or stage of development that an individual is going to be blind because of the nature of the physical eye abnormality. Sometimes vision cannot be predicted; for example, when the optic nerve is underdeveloped (optic atrophy). Some individuals have normal eye findings, but the cerebral center for vision in the occipital part of the brain is nonfunctional. In such cortical blindness one might have to wait for neurological maturation well beyond the age of three months before it can be absolutely determined that an individual is functionally blind. Observation of tactile search (in preference to visual exploration) might confirm that central blindness is present, requiring about five to six months mental development. Most cortically blind individuals usually have a variety of other neurological abnormalities, and it might be years before their blindness can be confirmed.

An occasional child with a severe neurological impairment might appear to be blind in early infancy, but then slowly develops useful vision over the next few years. Many of these children develop what can be labeled as visual imperception, a type of visual problem sometimes encountered in multiple and severely handicapped children. The term refers to the visual behavior of a child with normal eyes and obvious vision (he or she might spot desired objects across the room), but this child does not use vision either for communication or for obtaining information. Children with visual imperception might benefit from intensive visual attention training programs; thus, they might be correctly labeled visually impaired, if necessary, for educational purposes. In contrast, the main difficulty of children with visual-perceptual-motor problems is carrying out a motor act in the seeing-perceiving-doing sequence like copying a square. The neurological impairment of children with the latter kind of problems tends to be subtle, and they are not visually handicapped. Strabismus (cross-eyed) and nystagmus (rapid to-and-fro eye movement) do not constitute a visual handicap, but for other reasons, they are common symptoms in children who are visually impaired.

Mental development of at least three to four years is required to cooperate in the testing of visual acuity. Many children need services for the visually impaired before they have reached that stage of development. They can properly be labeled potentially or possibly visually handi-
capped to receive such services. If it is important to know how much a child can see before he or she is able to participate in vision testing, such information can now be obtained by using visually evoked EEG responses. However, this testing does not tell how a child processes what he or she sees.

Hearing Handicaps

In 1937 the Committee on Nomenclature of the Conference of Executives of the American Schools for the Deaf gave the following definitions of hearing impairments, which still are generally accepted:

Deaf A person in whom the sense of hearing is nonfunctional for the ordinary purposes of life
Hard of hearing A person in whom the sense of hearing, although defective, is functional with or without a hearing aid

Audiometric measures have also been used in discriminating between these two populations. Usually a hearing loss of 90 db or greater across a speech frequency range of 500 to 2,000 Hz is used as a cut-off point between the two populations. Conventional divisions or degrees of hearing loss are based on audiometric testing in which the cut-off point between normal hearing and a mild hearing loss is arbitrarily set at 25 db (mild, 26 to 40; moderate, 41 to 55; moderately severe, 56 to 70; severe, 71 to 80; and profound, 91 or greater).

Any repeated startle reflex to a loud noise without any visual or tactile component (like a telephone signal) would rule out total deafness in the first few weeks of life and in children who function on a very low level. A specially trained and equipped audiologist should be able to confirm the presence of deafness or profound hearing losses in young children who are able to turn their head to sounds (seven to eight months development). A mild, yet significant, hearing loss can be ascertained when a child is able to be conditioned to give a behavioral response on cue (for example, put a ring on a spindle in response to an auditory signal) at approximately a two-year developmental level. Most early testing has to be done free field (without earphones) and tests the hearing in the best ear only. Testing of each ear separately is dependent on a child's acceptance of earphones, a behavioral rather than a developmental factor. Sometimes young babies can be taught to use them. A four-year developmental level is required for a child to respond adequately to hearing tests conducted by nonaudiologists such as speech therapists and physician assistants. Concerns about hearing are very common for children who have not yet reached developmental levels which allow for even rudimentary testing. In such children auditory evoked EEG responses can be used to ascertain whether the hearing apparatus (middle and inner ear plus the hearing nerve and center) is functioning, but it does not reveal how the child processes what he or she hears.

The understanding of language (whether verbal, signed, or read) is fundamental for human interactions. Normally, children build their own expressive language on their understanding of the language they hear. Understanding of language (receptive language) precedes the child's first word by several months. Expressive language delay is a common parental concern, and a hearing loss is one of the first things to consider in a slow talker.

In children with any other handicap, the possibility of a hearing loss should be considered until it is proven through conclusive testing that their hearing is normal, which might take a long time in the severely handicapped. The aim of hearing testing of such suspect children, and all seemingly normal children, is to find the occasional child who would benefit from a hearing aid or medical treatment. A hearing aid cannot, and should not, be prescribed until hearing testing has been conclusive. As a result of the state of the art of hearing testing, a large number of suspected hearing loss individuals have been detected among the severely handicapped, but very few of them wear a hearing aid.

The possibility of severely disabled children being hearing handicapped is not just a theoretical concept; it has practical implications for education. Some severely and profoundly retarded individuals who lack verbal communication can learn to communicate in sign language. Surprisingly, even the totally blind, nonverbal but hearing (multiple handicapped) children have been taught to understand and use simple signs.

Mental Retardation

The American Academy on Mental Deficiency (AAMD) has adopted the following three-part definition of mental retardation.

Mental retardation refers to (1) significantly subaverage general intellectual functioning; (2) existing currently with deficits in adaptive behavior; and (3) manifested during the developmental period.

The AAMD makes no reference to etiology in the definition. Intellectual functioning may be assessed by using a standardized intelligence test developed for that purpose. The term significantly subaverage refers to a performance which is two or more standard deviations below the mean of the
test used, an IQ of approximately 70. The term adaptive behavior is defined as effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his or her age and cultural group (AAMD has an adaptive behavioral levels scale by age). The upper age limit of the developmental period is placed at eighteen years of age. This definition was arrived at after years of argument and is still being disputed. Mental retardation is the handicap which is most feared. It is the label most often misused by both the public and professionals.

The definition indicates that it should be possible to administer a standardized intelligence test before the label of mental retardation is appropriately considered. The test requires a mental age of approximately two-and-one-half to three years. Younger children are given developmental rather than intelligence tests. Even though poor performance on good developmental assessment tools is a reasonably good predictor of later significant mental handicaps, young children should be considered potentially mentally retarded until they can be adequately tested. Early development reflects a rapid increase in motor skills, and developmental tests are therefore heavily laden with motor tasks. Motor development is poorly correlated with what is later called intelligence. These two facts explain why developmental testing does not necessarily predict intelligence.

Mental retardation is usually considered a slower than average unfolding of development in a normal sequence. However, it is not necessarily true. A purely mentally retarded individual (one without any other handicaps) is probably going to function in the mildly retarded (IQ approximately between 50 and 70) range. The early development of such persons is usually unremarkable. Motor development is within normal limits, which incidentally are wide. The difficulty in problem-solving that is characteristic for mentally retarded persons is most likely to be reflected early in poor play skills. The discerning observer will note that the infant's interest in toys is limited, and his or her manipulations of them are stereotyped and lack goal direction. Normal infants usually put everything in their mouths, but by the beginning of the second year most children have developed a whole repertoire of play behaviors: cubes go in and out of cups and other containers or are stacked one on top of the other; balls are rolled; and a crayon is used for scribbling. All toys do not end up in the mouth! Another characteristic of mental retardation is difficulty with abstract thinking. One should be concerned about infants who, by the end of their first year, fail to develop evidence of stranger anxiety or some form of behavior which indicates that they have discovered that there is a difference between the people who normally take care of them and the rest of humanity. Another result of difficulties with abstractions is delayed understanding and use of language. Parents might not be aware that children respond to their names around nine months of age and to instructions such as "give it to me" by one year of age. But they are likely to become increasingly concerned if "mama" and "dada" and other meaningful words fail to appear during the first half of the second year. Delayed talking is the most common developmental concern in young children. In some of these children, but by no means in all, the delayed expressive language indicates mild mental retardation and is the first symptom noted by parents and caretakers. Mild is stressed because it is quite unusual for individuals with IQs of less than 50 not to have other handicaps which also interfere with development. Severely and profoundly mentally handicapped older individuals usually have so many additional disabilities that they are more accurately labeled multiple handicapped rather than retarded. They seldom reach a level of functioning which allows for intelligence testing as defined in the official definition of mental retardation cited above.

The second aspect of the definition of mental retardation is also important. Additional evidence of inadequate adaptive behavior is required before a person can be labeled mentally retarded. Therefore, many preschool children and adults are not mentally retarded. If one functions adequately in his or her society, he or she is not retarded, even though he or she may have a low IQ. If such a person needs special education during the school years, the label is appropriate only during those years. This aspect of the official definition of mental retardation is aimed primarily at protecting those individuals with retardation symptoms for social reasons. When the stigma of this label is considered, the adaptive aspects of the definition of mental retardation should also be required before labeling individuals with retardation symptoms on IQ tests for medical reasons.

The implication of the third part of the definition that mental retardation originates during the developmental period—usually considered to be up to adolescence—is self-evident.
Cerebral Palsy

Cerebral palsy is usually defined as a group of disorders in which nonprogressive damage to the brain results in motor disability. Many of the subclassifications are based on the type of motor disability, topography, and degree; functional disability is also sometimes considered.

The most commonly encountered types of cerebral palsy are spastic (increased muscle tone), hypotonic (decreased muscle tone), athetoid (fluctuating muscle tone), and ataxic (disturbed balance). Topography refers to a designation of the extremities involved. The most commonly used terms are quadriplegia (all four extremities), diplegia (legs affected more than the arms), hemiplegia (the arm and leg on one side), paraplegia (legs only), and monoplegia (one limb only). Degrees of disability are usually rated from mild to moderate to severe, with frequent use of in-between stages (mild-moderate and moderate-severe). Designation of severity according to functional disability (rather than the clinician's arbitrary judgment) is also used; practical limitations in daily activities are rated in four classes from none to severe limitation (inability to carry on any useful activity).

Cerebral palsy encompasses such a variety and degree of abnormal symptoms that it is difficult to make meaningful statements about its developmental aspects. Swallowing and sucking difficulties in early infancy are common. Mothers of older cerebral palsy children often tell of early feeding problems. Irritability and unusual and persistent crying are other complaints. A careful examination of infants who will develop cerebral palsy later reveals interferences in the orderly neurological development (appearance and disappearance of the primitive reflexes) and retarded motor development coupled with abnormal patterns of posture and muscle tone. Many of these early symptoms are subtle and detectable only by a highly trained observer. One should be suspicious if the baby has head lag when pulled to sitting (four months) and does not reach and grab (six months). If head lag is coupled with total leg extension, or the attempt to reach is hindered by wavering and imprecision, it is possible that cerebral palsy is interfering with the infant's development. The most likely cause in the first instance is spastic diplegia, while athetoid quadriplegia may be the cause in the second instance.

Hypotonia is apparent in early infancy and is usually noted right after birth. The floppy infant may suffer from a variety of disorders, but hypotonic cerebral palsy is one of the etiologic considerations. Most authorities agree that a significant number of spastic cerebral palsy cases are detectable by the age of eight months. The presence of athetosis and ataxia should be detectable during the second year of life.

The greatest problem with this handicapping condition is the length of time it takes for the type and extent of involvement to become apparent. The symptoms of cerebral palsy are especially dependent on brain maturation and, therefore, they change over time. Transient hypotonia is common in infancy in both the spastic and athetoid type of cerebral palsy. The presence of spastic cerebral palsy might not be confirmed until the end of the first year, when neurological maturation usually allows weight bearing on the legs. Then, extensor spasticity of the legs becomes apparent, and the legs are noted to scissor. In athetoid forms of cerebral palsy, many months may be required for the symptoms to develop. Most children with symptoms of cerebral palsy must reach a chronological age of about four years before the full extent of the disability can be elucidated. The assessment of cerebral palsy is dependent on chronological age rather than developmental age. Patient cooperation is not needed as it is for vision, hearing, or intelligence testing. The findings in cerebral palsy are also relatively objective.

In some cases of cerebral palsy, motor disability is so incapacitating that it obscures the developmental picture. Mislabeling is common in children with severe degrees of cerebral palsy; these children are frequently considered retarded. The term locked-in child syndrome has been coined to describe the child with an extreme degree of cerebral palsy and normal intellect. In these children the motor disability prevents not just gross-and fine-motor progress, but communication is also impaired. Social response (smiling appropriately) and eye movements (looking to signify understanding) might be the only response mechanism available to such children in whom the motor disability also prevents expressive language.

Some form and degree of cerebral palsy is the most common symptom in children with multiple handicaps, and mild forms are commonly overlooked in children with other major primary handicaps.

Autism

Most authorities now agree that autism is a continuum of behaviors which severely affect the social and communicative aspects of child develop-
ment. In 1961 a committee referred to as “The British Working Party” developed the following criteria for the diagnosis of autism: (1) gross and sustained impairment of emotional relationships with people; (2) apparent unawareness in a child of his or her own personal identity (inappropriate for age); (3) pathological preoccupation with particular objects; (4) sustained resistance to change in the environment; (5) abnormal perceptual experiences; (6) acute, excessive, and seemingly illogical anxiety; (7) speech and language abnormalities (confusion of personal pronouns, echolalia, and so forth); (8) distortion in motility patterns; and (9) islet of normal or near normal intellectual functioning on a background of serious retardation.

Autism was first described by Leo Kanner in 1943. He blamed it on cold and unresponsive parenting. Even though this theory has been discredited, a diagnosis of autism is still too often equated with bad environment, usually inadequate parenting, by uninformed physicians, educators, and other professionals. Autism, as it is well known today, is a symptom in many well-defined medical conditions like untreated PKU (phenylketonuria) and maternal rubella. Modern authorities agree that the basis for autism is a neurological disorder or, more likely, that autism is a symptom in a variety of neurological conditions.

The deviation in social development, so prominent in children who later are labeled autistic, is present from early infancy. These infants do not respond to normal mothering. They do not anticipate being picked up; they do not respond to being handled; they do not look at people’s faces; and they fail to smile responsively. Because of the inaccuracy of the definition and the vagueness of the symptoms of autism, the type of behavior differentiation present in a four-to-five-year-old child usually is needed before an informed judgment can be made as to whether the child’s behavior fits into this general category. A tentative diagnosis of autism can be made in younger children.

Children with the symptoms of autism, as previously described, are rare. Children with autistic or autistic-like behavior patterns are not uncommon among the severely disabled. Spinning, twirling, lack of eye contact, use of people as objects rather than persons, sniffing and licking to explore objects, and many other autistic features are common in populations considered primarily retarded, blind, or deaf.

Epilepsy
A treatise on multiple handicaps is incomplete without a mention of the epilepsies. These are defined as periodic, uncontrolled motor discharges or transient loss of consciousness or both. Grand mal seizures are the best known and are usually associated with epilepsy. They consist of violent, jerky motor movements accompanied by unconsciousness and are usually followed by deep sleep. Other seizures are less dramatic. Brief episodes of eye blinking, staring, or head nodding might represent seizures. In fact, any stereotyped behavior which lacks relationship to environmental circumstances should be suspected to be a seizure disorder, especially in children and persons with any kind of handicap. Epilepsy is present in otherwise normal persons, but its incidence is much higher in handicapped populations.

Other Labels
For completeness, the definitions of three other commonly used labels are given in the following paragraphs:

Learning disability. The National Advisory Committee on Handicapped Children has developed the following definition for this label:

Children with special learning disabilities exhibit a disorder in one or more of the basic psychological processes involving understanding when using spoken or written language. These may be manifested in disorders of reading, thinking, talking, reading, writing, spelling, or arithmetic. They include conditions which have been referred to as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, developmental aphasia, and so forth. They do not include learning problems which are due primarily to visual, hearing, or motor handicaps; mental retardation; and emotional disturbance.

Developmental disabilities. The Developmental Disabilities Act of 1963 specifies the following:

Developmental disability means a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary of the U.S., Department of Health, Education, and Welfare to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such an individual attains age 18, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such an individual.

Deaf-blind children. Recent federal regulations give the following definition of this population:

The term deaf-blind children means children who have auditory and visual handicaps, the combination of which causes such severe communication and other developmental and educational problems that they cannot properly be accommodated in special education programs solely for the hearing handicapped or the visually handicapped child.
Developmental Effects of Pure Handicaps

A review of how specific handicaps affect human development is summarized in the following paragraphs:

Vision impairment. Visual impairments, especially blindness, might cause a slight delay in motor development and in some self-help skills.

Hearing impairments. Hearing impairments cause a delay in language development and might secondarily retard abstraction ability.

Mental retardation. Mental retardation slows development of problem-solving and abstraction skills and puts a ceiling on such development which depends on the degree of retardation.

Cerebral palsy. All forms of cerebral palsy delay motor development, gross or fine or both. Secondary delay, in self-help skills are common, and expressive language delay might occur.

Autism. Autism causes delays in social development, which usually affects communication.

Epilepsy. Epilepsy per se has no significant effect on development.

Multiple Handicapped Children

Most individuals with significant developmental disabilities are multiple handicapped because the biological insults which cause such handicaps affect many body symptoms, and the brain, which usually is affected, determines such a variety of behaviors. Older multiple handicapped persons are most likely to be found in the mentally retarded population in institutions and group homes. Children who are multiple handicapped can be found in programs for the visually impaired, hearing handicapped, and cerebral palsied, as well as in programs for the mentally retarded.

The most common secondary handicap which needs remediation is cerebral palsy. The most difficult problem to detect is a hearing handicap. The possibility of a hearing handicap should be pursued until it is proven conclusively that hearing is normal. Visual handicaps are frequently obvious because physical eye abnormalities call attention to their presence, and visual pursuit is such a low-level activity. Some individuals with normal eyes might be cortically blind. This condition is detected when one observes persistent tactile exploration. Some children with technically normal vision have visual imperception and can benefit from visual training. Whether mental retardation is a primary or a secondary problem is usually a moot point. Most severely disabled persons are functionally retarded, except for an occasional profoundly physically afflicted person with cerebral palsy—the so-called locked-in-child syndrome. Autistic behavior patterns are common among the severely disabled. A primary diagnosis of autism signifies a neurological impairment of unknown etiology, and the possibility of other handicaps should be kept in mind.

Incidence of Multiple Handicapped Individuals

The incidence of multiple handicapped individuals is not known. In fact, incidence figures usually given on single handicaps are probably inaccurate because of difficulties in definition. In the epidemiological studies used to determine the incidence of handicapping conditions, the multiple handicapped individuals are counted two, three, or four times, depending on how many handicapping conditions they have.

An idea of the incidence of handicapping conditions can be obtained by studying etiological factors. This methodology is not the most accurate one for predicting the different handicaps that are present in our society, but it can be used profitably for regional comparisons. A comparison of the etiologies of multiple handicapped persons in Seattle, Washington, and American Samoa might contribute some practical information for use by the Southwest Region Deaf-Blind Center in projecting needs for service. The etiologies of 59 multiple handicapped patients examined by the deaf-blind team in Seattle are listed in Table 1. The table shows that the largest group consists of maternal rubella syndrome children from the 1964-65 epidemic. The next largest group is "prenatal: unknown—structural and CNS." This terminology is used for children who have physical, congenital, minor, and/or major anomalies in addition to obvious brain dysfunction symptoms. The third largest group lacks the physical (structural) anomalies but shows evidence of CNS abnormalities of obvious prenatal origin. The three occipital encephaloceles have been listed separately; technically they belong in the prenatal/CNS group. In 80 percent of the cases, the etiology was of prenatal origin. Except for one case, 10 percent of the children with perinatal etiology were victims of unavoidable complications. The four trauma victims were all the result of head injuries sustained in motor vehicle accidents.

The etiologies of 26 multiple handicapped Samoan children are presented in Table 2. Forty-two percent of these cases, as opposed to 10 percent in Seattle, were post-natal, the majority of which were post-infectious. The reason for the high
Table 1

<table>
<thead>
<tr>
<th>Etiology of the Deaf-Blind (Seattle)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prenatal</strong></td>
</tr>
<tr>
<td>Chromosomal anomaly (Trisomy E)</td>
</tr>
<tr>
<td>Dominant gene (Tuberous Sclerosis)</td>
</tr>
<tr>
<td>Recessive gene (Ectodermal Dysplasia)</td>
</tr>
<tr>
<td>Intrauterine infection</td>
</tr>
<tr>
<td>(Rubella)</td>
</tr>
<tr>
<td>(Toxoplasmosis)</td>
</tr>
<tr>
<td>(CID)</td>
</tr>
<tr>
<td>(Unable to clarify)</td>
</tr>
<tr>
<td>Occipital encephalocele</td>
</tr>
<tr>
<td>Unknown-structural+CNS</td>
</tr>
<tr>
<td>Unknown-CNS only</td>
</tr>
<tr>
<td><strong>Perinatal</strong></td>
</tr>
<tr>
<td>Prematurity + complications</td>
</tr>
<tr>
<td>Perinatal asphyxia</td>
</tr>
<tr>
<td>Neonatal herpes</td>
</tr>
<tr>
<td><strong>Postnatal</strong></td>
</tr>
<tr>
<td>Trauma</td>
</tr>
<tr>
<td>Postmeningitis</td>
</tr>
<tr>
<td>Postencephalopathy (unknown)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
<tr>
<td>Subtotal</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

| **Subtotal** 47 80% |

Total 59

incidence of this mode of etiology in the Samoan sample is unclear, but the implications for professionals planning for the care of handicapped children in that area are obvious. The numbers of survivors of prenatal and perinatal biological insults are probably constant in both localities. Thus, the high percentage of post-natal etiology indicates that there probably is a higher absolute number of multiple handicapped children in American Samoa than there are in Seattle. Whether this observation can be used for a comparison between other South Pacific territories and the mainland is not known.

**Early Symptoms**

The infant and preschool age child who is a potentially multiple handicapped case is a special problem (Figure 2). Two groups of children are at risk—the child with an abnormal birth history and the child with more than one congenital abnormality. Early feeding and sleeping problems and poor growth are danger signals. Delayed motor and social development might be the first indication that something is not right. Delayed language development is usually present.

Young children with suspicious symptoms should be put in infant or preschool programs before the type and extent of their handicaps have been determined. However, these children should be assessed periodically by competent professionals. At a chronological age of four to five years, reasonably firm judgments can be made about the disabilities of a child who has been observed over a period of time. However, the goal in such careful supervision of young handicapped children is not just an accurate prognosis. The aim is appropriate intervention with stress on appropriate areas and the identification and prioritization of needs. The results of the evaluation are reviewed with the family and involved community people.

**Table 2**

<table>
<thead>
<tr>
<th>Etiology of Multiple Handicaps (Samoa)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prenatal</strong></td>
</tr>
<tr>
<td>Chromosomal anomaly (21)</td>
</tr>
<tr>
<td>Dominant gene (Tuberous Sclerosis)</td>
</tr>
<tr>
<td>Intrauterine infection</td>
</tr>
<tr>
<td>Unknown-structural+CNS</td>
</tr>
<tr>
<td>Unknown-CNS only</td>
</tr>
<tr>
<td>Subtotal</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>14 54%</strong></td>
</tr>
<tr>
<td><strong>Perinatal</strong></td>
</tr>
<tr>
<td>Trauma</td>
</tr>
<tr>
<td>Postinfectious</td>
</tr>
<tr>
<td>Trauma or infection</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
</tr>
<tr>
<td><strong>11 42%</strong></td>
</tr>
<tr>
<td><strong>Unable to classify</strong></td>
</tr>
<tr>
<td><strong>1</strong></td>
</tr>
<tr>
<td><strong>Grand Total—26</strong></td>
</tr>
</tbody>
</table>

**Summary and Conclusions**

Most severely handicapped individuals are truly multiple handicapped. Early symptoms are vague and difficult to pinpoint. The best way to review the developmental aspects of handicapping conditions is during the early years with evaluation and periodic assessment by an interdisciplinary team.

Much physical disability is preventable. Much of the wasted potential of the individuals in our institutions today could have been saved if there
Fig. 2. Age at appearance of handicapping conditions
had been early identification of the various multiple handicaps, followed by appropriate intervention in early childhood. Hopefully, we are doing a better job with the present generation of multiple handicapped people, a population that will always be with us.

References


Corrective Therapy for the Deaf-Blind and Multihandicapped Individual: Identification, Developmental Assessment, and Training

Georgia L. Granberry
Certified Corrective Therapist
Program Coordinator
Ellisville State School Residential Deaf-Blind Program
Ellisville, Mississippi

What is corrective therapy? The Board of Governors of the Association for Physical and Mental Rehabilitation has defined corrective therapy and adapted physical education as the application of the principles, tools, techniques, and psychology of medically oriented physical education to assist the physician in the accomplishment of prescribed objectives. Corrective therapists work primarily in hospitals, rehabilitation centers, or similar institutions, while adapted physical educators work primarily in an educational environment; however, this does not imply that either is limited to these specific areas. Corrective therapy and adapted physical education are based on medically oriented physical education and use the same tools, techniques, and methods.

Exercises, Activities, and Procedures

The exercises, activities, and procedures listed below are used by the corrective therapist and the adapted physical educator in treating and/or programming for individuals:

- Extremity exercises
- Reinforcement exercises
- Hemiplegic exercises
- Paraplegic exercises
- Digital exercises
- Mobilization exercises
- Buerger-Allen exercises
- William's exercises
- Gravity exercises
- Nongravity exercises
- Therapeutic swimming
- Balance exercises
- Apparatus exercises
- Post-operative exercises
- Developmental and habilitative exercises
- Coordination exercises
- Codman's exercises
- Mat exercises
- DeLorme exercises
- Conditioning exercises
- Self-care activities
- Activities of daily living
- Elevation techniques
- Instruction to the blind and low vision patients
- Stump strengthening exercises
- Reciprocal exercises
- Isometric "muscle setting" exercises
- Postural exercises
- Orthopedic exercises
- Paraplegic procedures
- Low organizational games for the neuro-psychiatric patients
- Prosthetic training
- Gait training and progression ambulation
- Tests and measurements

As a corrective therapist, I have been involved in the identification, developmental assessment, and training of deaf-blind and multihandicapped individuals. My involvement in these processes has been primarily with an interdisciplinary team, on which each member learned much about the other members' particular specialties, thus enabling the team to function on occasion without one member.

Definition of Corrective Therapy

Mason and Dando (1965) defined corrective therapy as follows:

... The application of medically prescribed therapeutic exercises and activities in the treatment of the mentally and physically ill patient; not only for treatment of the physical disability, but also for the improvement of the psychological and sociological aspects of disease and illness.

This definition stresses that the aim of the corrective therapist is the treatment of the whole individual.

Early identification of deaf-blind and multihandicapped individuals is most important if appropriate training and referral is to be provided. To make appropriate referrals, the therapist must be familiar with all agencies and the services that they provide.
Patient Observations

In addition to medical history and diagnosis, which may or may not indicate vision or hearing problems, the following observations could be beneficial to a physician; an ophthalmologist; an audiologist; a neurologist; a physical, corrective, and occupational therapist; and educators:

1. Does the child visually attend? If so, is it to a large object, a parent, a small object, and so forth?
2. Does the child visually track? If so, how? Does the child just move his or her eyes or turn his or her head with his or her eyes remaining fixed?
3. Does the child respond to the sound of the voice, a hand clap, or a bell? If so, is it with an eye blink, a startle response, a smile, or a cry?
4. Does the child reach for objects? If so, what size object and at what location?
5. Does the child over and/or under reach? Note the location.
6. Does the child turn to sound? If so, how? Does the child just cock his or her eyes in the direction of sound or turn his or her head in the direction of sound with no eye movement as if looking for sound, and so forth?
7. Does the child grasp objects? If so, how? Does he or she use the palmar grasp with or without tucked thumb, finger-thumb opposition, and so forth?
8. Does the child have head control? Describe.
   a. When lifted at the shoulders in a prone or supine position, does the head lag or does the child bring the head into the neutral position?
   b. When held under the arms, does the head flop or does the child maintain it in a neutral position (upright)?
   c. When laid on your shoulder, does the child lift his or her head off your shoulder? How long can he or she do this?
9. Does the child sit supported? Describe the support.
   a. The child sits with side and back support.
   b. The child sits on the floor in “Indian fashion” propped or extended arms.
   c. The child sits on the floor in “Indian fashion” with his or her hands propped on the knees.
10. Describe any abnormal responses or suspected developmental delays such as:
    a. Moro reflex
    b. Strong sucking reflex
c. Involuntary extension thrust
d. Asymmetrical tonic neck reflex
11. Describe any suspected musculoskeletal anomalies such as:
    a. Beginning scoliosis
    b. Hip subluxation or dislocation
    c. Fixed contractures
    d. Inward/outward rotation of feet
e. Scissoring of legs

These are only a few of the observations I make during the evaluation of a child. The interdisciplinary team I work with is concerned with identifying the child's strengths and weaknesses in all areas of development so that appropriate programming can be made. I am particularly concerned with making referrals to an orthopedist when there appears to be a musculoskeletal anomaly which can be treated with preventative measures rather than having the child undergo surgery at a later date. Some preventative measures are (1) appropriately designed chairs to prevent spinal curvatures and to provide the child with a better position for certain types of training; (2) corrective shoes and short leg braces to possibly prevent severely rotated feet and possible heelstring shortening; and (3) proper handling techniques and sitting positions. Surgery on these children tends to cause regression not only in motor development but also in all areas of development.

I prefer to have the parents present during the evaluation of their child. This affords me a better opportunity to give them an idea of what I see, and, if needed, to teach them some proper handling techniques, which could make their lives easier and at the same time help the child in making developmental progress.

I have found through my contact and work with parents of deaf-blind and multihandicapped children that the therapist sometimes does not listen to the parents' questions or concerns about their child's vision, hearing, and development. Some parents indicated that they were not given help or told what to do for their child except to take the child home and leave it. In some instances they indicated that they were told that nothing could be done for their child, except for institutionalization. This is not the kind of advice most parents want to hear. Most parents know when their child is not progressing as he or she should; therefore, they need direction from us in regard to what they can do to help or advice as to which agency can give them assistance with their child.

Every deaf-blind and multihandicapped child can make developmental progress. The level of
functioning each child can attain is dependent on many variables; that is, medical history, early identification, developmental assessment, and appropriate training.

Training

Once the deaf-blind and multihandicapped child has been identified and assessed, what should be done? As a corrective therapist and an educator, I feel the next step must be training.

Parents are the most important asset. They usually can understand all of the medical and educational jargon if time is taken to explain it to them. I have found that this time is worthwhile for both the child and the family.

In training deaf-blind and multihandicapped children, programming must be based on sequential development. However, to do this, the functioning level of the child must be known. Behavior management techniques must be understood to avoid developing inappropriate behavior. Some understanding of the various types of vision and hearing problems is most beneficial so that one can better plan motor development activities by using any residual vision and hearing the child may have.

The motor development activities must be designed to bring the child through the normal sequential steps of development. These activities must meet the needs of each child. In planning the activities the therapist should keep in mind the person who is going to do them. A good example is the cerebral palsy child who has limited head control, little or no trunk control, and possibly goes into extension thrust. The parent should be shown how to carry the child, how to hold the child when seated, how to bathe the child in warm water, how to change the child's diapers and clothing, and how the family members can appropriately play with the child. All of these procedures should be explained so that they do not sound so overwhelming to the parent.

Classroom teachers should be taught handling techniques, proper sitting and lying positions, carrying methods, and so forth to provide the consistency necessary for enhancing the child's motoric development as well as other types of development.

Today, the corrective therapist and adapted physical educators can be and are involved in identification, developmental assessment, and training of deaf-blind and multihandicapped individuals. I have attempted to point out the following:

1. Importance of early identification and developmental assessment
2. Assistance one can provide in identification and assessment
3. Need for early appropriate programming
4. Need for consistency
5. Importance of the parent in training the child
6. Essentialness of an interdisciplinary approach with cooperation among professionals, para-professionals, and so forth

The most important point is that the training (programming) gets done and that the deaf-blind and multihandicapped individual is given the opportunity to reach his or her maximum potential.

References


Communication with Deaf-Blind Children

Martin L. A. Sternberg
Deafness Research and Training Center,
New York University, New York

A fundamental and pervasive problem in working with deaf-blind children is achieving adequate communication. Meaningful communication is basic to the success of all educational and habilitation efforts in work with these handicapped human beings.

Communication Modes

Through the years the following communication modes have been invented, tested, modified, adopted, or discarded:

- Fingerspelling in the hand with the American Manual Alphabet
- The LORM alphabet
- Writing in the palm
- Braille
- The Braille Alphabet Board
- American Manual Alphabet Wheel with Braille typing and script writing
- The Alphabet Glove
- Alphabet Plate
- The "Talking" disc
- The Moon Alphabet
- Tellatouch typewriter
- Hadley Tactaphone
- Viberadio
- Braille teletypewriter (TTY)
- Lipreading (visual)
- Lipreading (tactual)
- Tactile sign language
- Braille/tactual

Communication Needs

People who are deaf or who work with the deaf have become increasingly sensitive to the communication needs of deaf-blind persons. This increased interest and desire to be of help is due to a number of reasons. The rubella epidemic of 1964 produced many multihandicapped children, many with visual as well as hearing problems. Public Law 94-142 has served to draw together the different disability groups; organizations such as the American Coalition of Citizens with Disabilities have further increased the feeling among disability groups that they are actually all members of one large disabled population. The recent White House Conference on Disabled invididuals added yet further to this developing feeling of solidarity, or the desirability of working together for the rights of all disabled citizens.

The major impetus for increased awareness of the communicative needs of the deaf, visually impaired person, however, came about as the result of the great sign language explosion which began in the mid-1960s. Energetic new efforts were made to develop and extend sign language systems for use by deaf persons, particularly children in the classroom. This total communication concept was the result of growing dissatisfaction with an oral-only approach to communication with deaf children. The deaf child's individual differences and needs had to be recognized; the communication modes had to be tailored to these needs so that optimum learning could take place.

Extending this concept to the deaf-blind community was a logical and natural by-product of the stepped-up awareness and activity in the field of communication with deaf persons. Lee Brody, a hearing impaired person, was responsible for the development of the Braille teletypewriter (TTY).

Sign Language

Many children who have been classified as deaf-blind have some residual sight. Since they do not have useful hearing for speech, sign language would be the most promising means of instructing them. However, the differences between signs in the American Sign Language (ASL) sometimes involve movements too small for these children to detect. The problem, therefore, is to magnify signs within ASL so that they can be used to communicate with deaf-blind children.

Several years ago the Deafness Research and Training Center of New York University undertook the development and field testing of a system of modified sign language for deaf-blind children. The site chosen was the New York Institute for the Education of the Blind, and the project was...
The New York Institute has a large deaf-blind center, Frampton Hall, serving approximately 75 deaf-blind children, a large number with severely limited but still functional vision.

Meetings were held in early 1973 with the 35 teachers of these children. From these discussions emerged a list of approximately 500 concepts for which signs were needed. The deafness center's manual communications staff then scrutinized each sign for its visibility. The standard signs were also tried with the deaf and visually impaired children.

For any sign judged insufficiently visible, a logical substitute was devised. The new sign had to be clear to the child and had to have some sign logic in its construction. Once the vocabulary was complete, the teachers began to use it in daily instruction. Feedback from the teachers confirmed the usefulness of most of the signs. Those found objectionable were replaced.

The final field-tested vocabulary was filmed in 16 mm color. In addition, the signs were described in a manual which shows each one in its position in the film. The film was edited and duplicated for distribution to each of the ten regional centers for the deaf-blind. The film consists of 10 reels which are broken down into teaching units. The total running time of the 10 reels is 2 hours and 10 minutes. The signs are shown individually and in context with practice sentences. The manual enhances the package as a self-instructional program for teachers and after-school personnel who can use it to refresh their memories on how to make a sign or to locate the sign on a specific reel. Teachers and after-school staff, in turn, can use the signs with the children. Certain children, mostly older, who are able to use residual vision can also benefit from direct viewing of the film.

The basic sign vocabulary is significant in two ways. Most importantly, it breaks down the major barrier to communication with deaf-blind persons. Spelling in the hand is not easily mastered. For low-verbal deaf-blind persons, especially young children, signs offer a more easily mastered communication mode. In turn, this improved communication should translate into increased habilitation of these severely disabled persons.

Secondly, acceptance of these signs by the ten regional centers for deaf-blind children and by the Helen Keller Center for Deaf-Blind Youths and Adults means that sign language used by the deaf-blind will be standardized. Standardization has not been achieved among deaf signers who use many competing systems as well as a number of variations on individual signs. In a deaf-blind community, communication should be greatly enhanced, regardless of the deaf-blind person's place of origin.

The vocabulary was developed to reflect communicative needs in a school for young deaf-blind children. Each reel of film covers a family of signs: (1) alphabet, numbers 1 through 10, days of the week, and colors; (2) family and relationships, pronouns, and the verb "to be"; (3) verbs; (4) prepositions and connectives, and clothing; (5) question words, house, and furniture; (6) adjectives, time and related signs; (7) food; (8) miscellaneous nouns and geography; (9) school and animals; and (10) body and health.

Teachers have been uniformly enthusiastic about this project and have reported many cases of major communicative breakthroughs with their children. Even the most severely disabled have frequently benefited through increased self-awareness and responsiveness to the environment.

The Deafness Research and Training Center is contemplating a second project with the older children of this population who are taking vocational training. The objective of the project is to select, modify, construct, and evaluate between 750 and 1,000 signs for use in vocational education with deaf-blind students between nine and twenty-one years of age. The signs will be visually distinguishable by deaf students who have some functional vision. This group is severely disabled and is in need of the services that would be provided by this project.

The project will produce its vocabulary by (1) compiling a list of words essential to the vocational education of deaf-blind individuals; (2) evaluating existing ASL signs for these words; (3) constructing new signs to represent words for which no signs currently exist; (4) modifying signs which are insufficiently visible or distinguishable; (5) testing the visibility and distinguishability of the signs with a sample of deaf-blind students; (6) instructing the vocational education staff of the Mid-Atlantic North and Caribbean Regional Deaf-Blind Center in the use of the signs; (7) altering the signs as needed according to reports by teachers and counselors of the actual vocational-education value of the signs; and (8) evaluating the impact of the signs on communication skills and vocational-education progress of deaf-blind students.
Summary and Conclusions

The combined effects of deafness and blindness are most evident when communication is attempted. Most of the available communication methods are either too slow in use, difficult to teach, or both. Modified signs—traditional American Sign Language signs, if possible, and specially altered signs that enhance intelligibility—have been shown to improve communication with deaf-blind persons (Sternberg, Tipton, and Freebairn, 1976). Signs for use in vocational education have not yet been developed and are urgently needed.

This project should be expanded to include input and suggestions from all regional centers for deaf-blind children. While modified manual communication for deaf-blind children has in the main focused on deaf children with severely limited but still functional vision, it is hypothesized that this same communicative mode may have relevance for tactile sign language communication with deaf and totally blind individuals. Some deaf persons who became blind later in life have been very successful in communicating through the tactile sign language. In many cases they prefer it over tactile fingerspelling and Braille. Manual communication in general and modified manual communication in particular need to be further developed and applied with our deaf-blind population.

References


A Total Approach for Increasing the Quality of Life for the Visually and Auditorily Impaired Child

Sandra Meyer
Consultant, Education of Deaf-Blind Children
John Tracy Clinic, Los Angeles, California

I would like to share with you one particular method of assisting the primary caretaker in the role of teacher of the deaf-blind child. Each of us may be involved in a different mode of intervention with definitive methods, but we are all working towards meeting the needs of a total person.

Background Information

A unique approach, based upon Learning Steps: A Handbook for Persons Working with Deaf-Blind Children in Residential Settings, is the basis of this paper. I feel, however, that it is important to provide background information on the development of this program. Four years ago the John Tracy Clinic Correspondence Learning Program for Parents of Preschool Deaf-Blind Children was completed. This correspondence education approach is used because it allows us to reach into homes across the country. It is an especially practical approach in assisting a low-incidence population for which there are very few services available. The multifaceted needs of this population can be best met with parent education and support: a consistent program to follow; a basis for building a coordinated program between home and day school, home and residential facility, or home and therapy services; and early intervention in the formative years of the child's development.

The Correspondence Learning Program has a unique feature which has been carried through into the development of Learning Steps. When the parents or parenting figures first contact the clinic for enrollment, they are asked to answer questions about their child. The questions are based on a brief developmental checklist. The information from the checklist provides a behavioral profile from which an individualized program can be established. This program takes into account the family's personal concern.

The total home-learning program is divided into two major parts: (1) twelve parent information and attitude sections and twelve lessons on communication; and (2) a series of tracks in seven different areas encompassing motor development and self-care skills. Visual impairment and hearing loss do not have an additive effect on the development and education of the child but rather a multiplicative effect. Oftentimes, other complicating factors will affect the education of the child. Therefore, because each child develops at a different rate in each area, allowances must be made for this individuality through a prescriptive program. With the information the parents provide on the application and checklist, training can begin with the total child in mind and with his or her individual needs taken into consideration.

Since many of the children do not live at home or in a home situation but in a variety of residential settings, Learning Steps is directed to the primary caretaker in these particular settings. In the past the role of the primary caretaker was often clearly defined under the medical model as one meeting the medical needs and physical well-being of the child. We felt the necessity of concentrating on the affective domain by addressing these surrogate parenting figures whose opportunities for teaching are limitless.

The successful and flexible multitrack approach used in the Correspondence Learning Program was maintained in Learning Steps. In the appendix at the end of this text is a checklist that can be used to help the child care worker determine the appropriate goal in any given area on which to begin work.

Communication Skills

From the day the deaf-blind child is born, his or her world is a confusing place, even a hostile one. Without the ability to hear the mother's affec-
tionate words, or without the ability to see her smiles and the love in her eyes, it becomes difficult, even in those early months, to feel secure and to build trust. But how about the mother who is filled with anxiety, fear, anger, and many other feelings which she transmits to her child through tenseness in the manner in which she cares for him or her? The child’s fear from not understanding what is happening results in a lack of responsiveness, which creates more insecure feelings in the parent. Thus, the communication that is being established is not helping to nurture a more positive relationship.

I have mentioned communication first because I feel that it is the fundamental building block of all other skills. The training techniques discussed in Learning Steps establish that training does not take place unless communication is an integral part of each interaction between the adult and the child. The majority of families with whom I have corresponded have mentioned communication as an area of most concern to them. We know that the development of language starts when the child is born. The way in which the mother interacts with the child feeds, diaries, or talks to him or her is communication. Parents, caretakers, and teachers then proceed to build language and work towards a formal communication system. When the child is born, it is not known what his or her primary source for developing communication skills will be. For this reason the parents and the primary caretaker are urged to talk to the child at all times, handling him or her with gentleness and respect. Begin by using natural gestures, and then use formalized sign language as fast as he or she learns the system. Every child has a right to learn a system of communication that will allow him or her to interact with as many people as possible. Indeed, it is out of respect for the child that the primary caretaker must include the building of communication skills as part of each moment of each day. The child has the right to have those around him or her care enough to build with him or her a formal system of communication, whether it be an oral system, a formalized sign system, or a combination of both. Natural gestures are used with the children, but unfortunately they may not be universal. Therefore, communication with those outside the home or the classroom may be limited. With a formalized communication system, opportunities will be available for the deaf-blind child and adult to participate in community programs, alternative work situations, and a wider variety of social situations.

If the child is not yet attending visually, cannot attend visually, or does not have enough hearing to attend auditorily, then the primary caretaker should take the child’s hand and form the sign on his or her body and talk to him or her. Only through communication will the child begin to build retrospective and anticipatory behavior and begin to understand what has happened and what is going to happen. Again, I emphasize that it is the child’s right to know what is going to happen to him or her, or what is going to happen around him or her. The parenting figure must be encouraged to offer mature guidance to the child. Language is a fundamental tool through which ideas are transmitted. Language should precede every activity, should be an integral part of every activity, and should certainly be used to recall or review any follow-up activity. Language transmitted through a formalized communication system is the basis for all teaching.

Body Language

As I previously mentioned, the first form of language a child receives is body language. An input of emotions is transmitted from the parent to the child through hugs, pets, and holding. When one holds the child close and sings softly or speaks in soothing tones, the child receives a feeling of protectiveness and love. When the parent is tense or upset, these feelings are also transmitted through the vibrations or tonal qualities of the voice, the tightness of the muscles, and the manner in which the adult holds the child. During this period of development in communication, receptive language is taking place. The parenting figure is “feeding in” language, but at this time the child is not yet returning or expressing language through words or signs. The child, however, is expressing language through his or her body movements, cries, tantrums, or emotional outbursts. The adult may sometimes become so intent on teaching the child a particular skill, or in caring for the child’s physical needs, that the language coming from the child is often ignored. Often the adult becomes angry at the temper outbursts or self-abuse the child may display. The adult needs time to step back and consider what might be causing the child’s unhappiness or outbursts.

The child may be confused as to what is expected of him or her. It is not unusual for the child to be grabbed suddenly by the arm and pulled into the bedroom or out the door and into the car for a journey to the store, to the doctor, or to a therapist. Consider how many medical procedures
these children have experienced in their first five years of life, plus many other consultations and educational evaluations. They are all necessary, but we must understand the child's fears when so many people are acting on his or her body, and he or she does not have a full understanding of the situation. Thus, the parents or the primary caretaker must be helped to be more sensitive to the communication that is coming from the child. The child is saying something in the only way he or she may know at this point in his or her life. Gradually, the adult can begin to institute some formalized language to help ease some of the frustration on the part of the child in expressing his or her needs or dislikes or fears. If the adult truly has respect for the child and his or her right to have feelings, thoughts, and likes and dislikes, the adult must make an extra effort to listen to the child.

Building Competence

When does one begin to help the child develop into a social, thinking human being? First and foremost, those who are in an advisory or guiding role must truly believe that these children can learn. Each and every moment of working with them can be exciting, because they can learn. Usually, the first task is to build competence in daily living skills. This task begins when the child is very young and he or she is participating in the normal home routine. No formalized lessons are needed, but development of self-care skills does require directed attention in thought and performance as the need occurs during daily routine. Therefore, Learning Steps can be used to help the adult incorporate language and techniques for developing skills in the normal routine used for caring for the child. The caretaker should never do for the child what he or she would like the child to do for himself or herself. It is time consuming to help the child through each and every task, to allow him or her the extra time to attempt to do it unassisted, and to encourage the child when he or she may forget the goal before completing the task. But in the end the adult's job will be easier. Even more important, the child will have moved another step towards independence. Certainly, it would be easier to continue to do things for him or her. The child will not stop you and say, "I want to do that for myself," as other children do. The child will have to be helped to build the confidence and the skills that he or she needs. Coaction, or patterning, can be used in the initial phase of helping a child to build a skill. The adult keeps his or her hand over the child's hand until the complete task has been performed. Use of patterning or coaction is also essential in building communication skills.

In Learning Steps the tasks are broken down into small increments so that the child may consistently achieve success. The adult is always present to offer physical and moral support, but the adult must have expectations, or the child will not have anything to live up to. The ability to use coaction is one that requires not only perception and a delicate balance in providing support but also knowing when to withdraw this support. I previously mentioned that the adult places his or her hands over the child's hands as he or she helps the child pull on a pair of pants. But the adult must be very sensitive to any slight movements that the child makes in expressing independence. The adult should start the child on an activity, slightly loosen his or her grip, and, pausing, let the child continue for a moment. Then, if necessary, the adult must tighten his or her grip again to support the child and encourage him or her to finish. Using coaction along with "backward chaining" has often proved successful. In backward chaining the adult's hands are over the child's hands while performing the task many times in natural situations. After the child has had repeated opportunities to experience this kinesthetic feeling of performing the task, the adult can then coact with the child through most of the task, but allowing the child the opportunity to complete the final step. Gradually, the adult can encourage the child to assume more and more independence in the steps to completing the task.

Routine and Pattern

Several times I have commented on the importance of attaching the correct language or words to the action that takes place. The pairing of the symbol with the action creates understanding and thus creates receptive, and, eventually, expressive language. However, another important and fundamental necessity in helping the deaf-blind child build anticipatory behavior is the development of generalized routine and pattern. He or she must begin to build an understanding of time sequence. People arise in the morning, eat breakfast, and go off to school or work. This routine changes at certain times, such as the weekends, holidays, and vacations. These can be times for pleasant anticipation, or times when leisure activities can be enjoyed. As a matter of fact, it is quite necessary not to be rigid in proceeding through every action or through each day. But there is a need to follow a generalized routine and to begin to build symbolic language in conjunction with this routine.


**Mobility Skills**

Along with the daily living skills of eating, personal hygiene, toilet training, and dressing, *Learning Steps* focuses on the importance of building ease in mobility skills. During the first few years of life, the child receives much help in building gross and fine motor skills. Fine motor skills are an integral part of developing daily living skills and communication skills. Gross motor skills help the child to establish awareness of self, to move about, and to stand up and, ideally, help the child to establish awareness of self, to skills and communication kills. Gross motor skills.

Building mobility skills also requires changing the child’s position during the time he or she is awake. The child who does not yet have head control may be propped up in a beanbag chair or infant seat, or supported with pillows so that he or she may sit on the floor. The child should also be placed in a prone and supine position on the floor so that he or she can reach out and attempt some movements. Some sort of incentive must be provided for him or her to move around and reach out—namely toys or interaction with other individuals. But the child should never be expected to amuse himself or herself, because ultimately his or her body becomes his or her playmate. Deaf-blind children frequently become involved in self-stimulating experiences. They experiment with their fingers, toes, saliva, hair, or any other part of their body that may bring them pleasure. Through playing with their bodies, they experience feelings of existence. To substitute or to begin to offer other alternatives of activities for the child, we should interject ourselves into his or her world by offering appropriate toys. The child should be offered enough alternatives to want more and more appropriate outlets for gratification.

**Choice**

The ability to make a choice begins as soon as the child is helped to become a separate person; that is, one who has rights. The child must be provided with the opportunity for choice from the time he or she is very young. Sometimes it begins with offering him or her cookies. Of course, the child is not able to say, “I would like this cookie rather than that cookie.” But when his or her attention has been gained, he or she may extend his or her hand and reach out for a cookie. The child will become an established fact through experience. At first he or she will accidentally reach towards a cookie, and it will be given to him or her quickly. But eventually he or she will learn to discriminate between cookies and will understand that he or she will receive whichever one he or she reaches for. The process of choice begins to take place. An action has been paired with a resulting effect, and choosing has become a conscious behavior. Gradually, the child will develop a more discerning and discriminating ability, according to his or her own likes or wants. He or she has the right to develop this ability, just as you and I have the right to make choices. What has been done is to limit his or her choices and provide freedom of choice within a prepared environment. Likewise, the same process can take place with crayons, cars,
or even dresses. Choice can be provided throughout the day in many different types of activities. Of course, choice is not always possible, but when it is possible to allow choice, it should be encouraged and nurtured.

Independent Action

As one works with deaf-blind children on developing competence in caring for their own needs, other important traits are being built in the child. Can he or she complete the task independently? Does his or her attention span allow him or her to stay with the task and see it through? Many approaches used in programs to teach children are on a one-to-one basis. Again, it is important to set appropriate goals so that the child can experience success; because success effects more success. Children, and even adults, want to continue behavior through which they receive approval and self-gratification. When the child is able, he or she should be allowed to undress himself or herself, even if it is only to remove his or her shoes. This act may be the first step in building his or independence.

Completing a task independently also requires the ability to follow directions. How are children taught to follow directions before they have learned a formalized language, or developed an ability to read print or braille? The ability to follow many directions can be learned through coaction, through the understanding built through routine, and by the establishment of anticipatory behavior. If the child has participated in a certain activity over and over again, he or she will have developed understanding through the kinesthetic approach of what is expected of him or her. The child should be able to move on to understanding directions through other means of communication as well: this is one reason why we move from three-dimensional objects to the two-dimensional plane. The three-dimensional object is used as one actually handles a piece of clothing or a utensil for eating and coacts with the child throughout the action. But three-dimensional objects are used in other activities of daily living skills in which the child is encouraged to follow a direction, learn a task, maintain his or her attention, and assume some responsibility. Emptying a wastebasket is a realistic beginning task for the child who is able to walk. However, the child must have been taken through this task many times by an adult. Perhaps the adult can then ask the child to assume this responsibility by merely lifting up the wastebasket. If the child understands the symbolic language of this gesture, he or she may be started on the two-dimensional plane.

The partially sighted child is included in the previously discussed procedure. A simple, black-lined drawing of the wastebasket should be the printed symbol. Again, a pairing process is used for matching the two-dimensional representation to the real object. After this process has been repeated over and over again, the adult should present the two-dimensional symbol to the child and allow him or her a chance to respond to the stimulus. If the child is unsure, the pairing process should be repeated again, and coaction should be used once more until the child responds to the picture of the wastebasket in assuming the responsibility for the task.

What about the child who has no vision—how can he or she be helped to move from the actual object to a representation of the object? Just as for the partially sighted child who may not yet read print, or for the totally blind child who does not yet read braille, a raised representation of the three-dimensional object can be made on heavy paper with a seamstress' wheel or pizza cutter.

Another very important section in Learning Steps is one that deals with play. What the future holds for children when they become adults should not be decided by the adults of today. However, it is our duty to help the deaf-blind individual work at living and work at being. The ultimate purpose of training and education is to teach him or her how to use leisure time when he or she is a child living at home, or an adult living in alternative living situations. The child will have much free time, and it is important that he or she be stimulated to reach out to the world around him or her. The child should not only develop a variety of interests, hobbies, and activities that he or she can enjoy alone, but he or she should also develop other leisure behaviors for participating in groups.

What is the rationale for achieving the above goals? A thinking, social human being is one who understands simple cause and effect and is able to assess an immediate problem. He or she is one who has the social amenities and niceties to make him or her desirable to be near. A parent once wrote:

I wish foremost for my child to be happy. I wish him to be educated to the extent of his abilities and capabilities. I would like him to have enough daily living skills so that he will not feel he is a great burden, to be able to wash and toilet himself as every grown man and woman can do. I would like others to be happy about being around him. I would like to see my child be content in using leisure time wisely, whether it be for his own self-
interest or whether it be in the community. I would like companionship for my child. I would like my child to have an appreciation of beauty that he can perceive, in whatever way is possible for him. I would like my child to be able to manage himself, so I am not afraid to leave him alone, and to have the ability to get himself out of a house or building in case of an emergency or a fire. I would like him to be able to communicate with a doctor or other professionals with whom he interacts, so he can tell them what his needs are. And at last I wish to God I knew how to help him accomplish these things.

References


## Appendix

### Learning Steps: A Handbook for Persons Working with Deaf-Blind Children in Residential Settings

#### Checklist

<table>
<thead>
<tr>
<th>Parent's name</th>
<th>Child's name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>State</td>
</tr>
</tbody>
</table>

Answer one or more items under each heading. The answers will help you in selecting the correct goals on which to start. A child can be at varying levels for different areas of development.

### Body Movement

- Making the child aware of himself or herself and his or her body
- Teaching the child to lift his or her head and chest
- Teaching the child to roll over
- Teaching the child to roll from back to front
- Helping to strengthen the child’s muscles
- Helping the child learn to sit up
- Learning to sit up
- Teaching the child to crawl
- Helping the child learn to stand
- Teaching the child to turn his or her body
- Helping the child crawl longer distances
- Helping the child learn to walk
- Helping the child learn to sit in a chair
- Helping the child learn to squat
- Helping the child walk longer distances
- Helping the child learn to go up stairs
- Teaching the child to go down stairs

### Eating

- Feeding the child from a spoon
- Teaching the child to drink from a cup
- Changing the child’s eating habits
- Helping the child learn to eat finger foods
- Preparing the child for chewing
- Teaching the child to chew
- Teaching the child to accept a variety of foods
- Teaching the child to feed himself or herself from a spoon
- Teaching the child to drink from a cup
- Helping the child learn to set his or her cup down
- Teaching the child to use a napkin
- Helping the child learn to pour from a pitcher
- Teaching the child to set the table
- Teaching the child to clear the table
- Teaching the child to eat with a fork
- Teaching the child to use a knife to spread food
- Teaching the child to cut his or her food with a knife
- Helping the child to prepare foods
- Teaching the child to wash dishes
- Teaching the child to put dishes away
<table>
<thead>
<tr>
<th>Dressing</th>
<th>Toilet Training</th>
<th>Personal Hygiene</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teaching the child to pull off his or her shoes</td>
<td>Teaching the child to pull a shirt over his or her head</td>
<td>Teaching the child to rinse his or her mouth</td>
</tr>
<tr>
<td>Teaching the child to pull off his or her socks</td>
<td>Teaching the child to pick up his or her clothes</td>
<td>Teaching the child to take a bath</td>
</tr>
<tr>
<td>Teaching the child to pull off his or her pants</td>
<td>Teaching the child to select his or her clothes</td>
<td>Teaching the child to wash his or her hair</td>
</tr>
<tr>
<td>Teaching the child to take off his or her shirt</td>
<td>Teaching the child to put his or her clothes away</td>
<td>Teaching the child to comb his or her hair</td>
</tr>
<tr>
<td>Teaching the child to pull up his or her clothes over his or her head</td>
<td>Crying the child to put his or her coat away</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to tell &quot;front&quot; from &quot;back.&quot;</td>
<td>Crying the child to unzip jacket or pants</td>
<td></td>
</tr>
<tr>
<td>Helping the child learn &quot;left&quot; and &quot;right.&quot;</td>
<td>Teaching the child to zip up jacket or pants</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to put on his or her shoes</td>
<td>Teaching the child to unbutton a belt</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to put on his or her socks</td>
<td>Teaching the child to buckle a belt</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to pull up his or her pants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching the child to put on his or her jacket or shirt</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Determining the child’s schedule</td>
<td>Teaching the child to use toilet paper</td>
<td>Teaching the child to rinse his or her mouth</td>
</tr>
<tr>
<td>Teaching the child “wet” and “dry”</td>
<td>Teaching the child to get up from the toilet</td>
<td>Teaching the child to take a bath</td>
</tr>
<tr>
<td>Using the bathroom at scheduled times</td>
<td>Teaching the child to put on clean pants</td>
<td>Teaching the child to wash his or her hair</td>
</tr>
<tr>
<td>Teaching the child to pull down his or her pants</td>
<td>Teaching the child to flush the toilet</td>
<td>Teaching the child to comb his or her hair</td>
</tr>
<tr>
<td>Teaching the child to take off his or her pants</td>
<td>Teaching the child to wash his or her hands</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to wash his or her hands</td>
<td>Teaching the child to tie a shoe</td>
<td></td>
</tr>
<tr>
<td>Teaching the child to keep his or her nails clean</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching the child to wash his or her face</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching the child to brush his or her teeth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching the child to use toothpaste</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Parent Counseling
Barbara Mills
Psychologist, John Tracy Clinic, Los Angeles, California

Parent counseling is an often overlooked dimension of the range of activities and skills that the professionals who work with deaf-blind multihandicapped children know and use. The professional's areas of expertise and accomplishments are numerous and diverse—they include various aspects of medicine, nursing, differential diagnosis and assessment, audiology, or community resources. Parent counseling, or getting involved with and teaching parents, is one of many interventions that are useful to the professional in accomplishing his or her primary goal of helping the deaf-blind child become a self-maintaining and self-actualizing person.

Virtually every interaction between the professional and the parents of the handicapped child is essentially a counseling or helping relationship. These interactions sometimes have subtle or very open emotional facets. Every time the professional talks with a parent, his or her words have a bearing on what the parent may think, feel, or do. The use of good interpersonal and counseling skills can maximize the effectiveness of one's abilities to work well with families. Counseling skills—the ability to convey understanding, warmth, and acceptance to another, and the ability to help others feel more comfortable with themselves in their life situations and to feel as capable colleagues in solving problems—can make many aspects of the professional's job easier and the results more productive.

Parent counseling is the procedure through which professionals can effect the most massive changes in the lives of the children with whom they are concerned. The quality of a child's nurturing, the development of his or her interpersonal relationships and self-concept, the subject matter he or she learns, the manner in which he or she learns to become a social being, and the eventual decisions about educational and residential programs are all dependent upon the psychological dynamics of the parents. Through parent counseling, professionals can help the parents with thinking and feeling through problems and decisions, living with their handicapped child, and understanding and accepting themselves and their child. When parents are comfortable with themselves, their emotions, and their attitudes; they are able to nurture their child and are receptive to productive input from other sources.

Most professionals who have worked with families of deaf-blind children probably know the personal and emotional levels of the hurt, the anguish, and the frustration they experience. They are familiar with stories of the seemingly inappropriate or inaccurate initial diagnosis, the unfeeling recommendations, the search for more and different expert opinions, and the questions of fault and blame. They know the stresses on the whole family—the resentments that build between parents whose roles and functions are permanently changed and upon whom unexpected and difficult burdens are placed. They are aware of the new value decisions parents must make; for example, the new and continuing balancing of priorities of time, energy, and money between the handicapped child and the other children in the family.

I recently sat in on a consultation session with the parents of a two-and-a-half-year-old boy who had developed normally for six months and then contracted meningitis. The illness had left the boy very disabled. He functioned at an age level of two to three months and had little or no vision and hearing. I asked his mother if he responded to being held. She answered with a sort of wry half-grimace and half-smile. As I talked more with the mother, she described how she had held, rocked, carried, and cuddled her disabled son for 10 to 15 hours a day for approximately two years. In addition, this pregnant mother managed to care for an older child. This case and many others are examples of continuing and constant stress and strain that are common in families of severely multihandicapped children.

The stresses are great, and they must be handled by parents at a time of personal vulnerability. Gail Stigen, a parent of a severely handicapped child, describes in her book, Heartaches and Handicaps, her feelings and those of many other parents.
Discovering the concrete fact that you have a handicapped child is a heart stopping, mind boggling, gut-level body blow. Some parents get it socked to them right at birth, others get it later. Some accept it, some reject it, some buckle under the strain, and some rise above the fact. All are consumed with an awful sorrow, not the surgical sorrow of death, but an hourly, daily, yearly sorrow, an agonizing, shattering, tearing sorrow.

How parents endure the burden of a handicapped child is certainly influenced by their inner resources, but they do not have to stand alone. Their ways of enduring can be profoundly and positively affected by professionals who allow them to find their own insights, charter their own paths, and find their own growing and constructive experiences. Professionals can provide praise, support, and alternatives, and can at times provide a shoulder for them to cry on.

One writer on the subject of handicapped children noted that the best single predictor of the level of achievement of a child with a disability is the strength, integrity, and emotional health of his or her family. These resources, in addition to the humanist desire to help parents to achieve higher, more comfortable levels of feeling in dealing with their child, and the unique social and personal problems the disability creates, are good cases for parent-professional involvement at a feeling level. They provide parents with something more than intellectualized objective facts.

Every interaction the professional has with the parents, whether it is intended or not, has an emotional impact on them. Even before their first meeting the parents are dealing with many feelings involving their appointment with the professional. Things the parents may be preoccupied with include attitudes and feelings that have nothing to do with the professional. Parents must deal with their feelings about authority figures, especially those in the medical field; they must deal with their feelings about handicaps and differences; and they must deal with the feelings that result from previous experiences with taking their child from doctor to clinic to therapy sessions. Much of how the parents react to the professional and the things he or she says are a function of the way they feel about themselves, their self-confidence, their self-concept, their feelings of ability to cope, and their particular patterns of reacting to stress and anxiety. Each time the professional has a meeting with parents, he or she can be sure that many emotional and attitudinal undercurrents will affect the interactions and the resulting outcomes. The professional, as a people-helper, can do much to help the parents clarify and feel more comfortable with him or her and with themselves.

As I think about how the professional works with parents and about the particular emphasis of a counseling approach, I also think of the goals that all of us rank as important achievements in our work with the children and their parents. I would like to list a few and emphasize that each of these goals is more readily attainable for most families when professionals develop and use the counseling skills described later. A few of the goals that can be achieved are (1) parents who are better able to care for and love the handicapped child and other children in the family; (2) parents who are more comfortable and accepting of themselves; (3) parents who are more open to searching for, examining, and accepting alternatives and input from others; and (4) parents who are more confident in their ability to cope with the realities of their lives. The professional can help parents become more able and more willing to involve themselves with their child's therapy, activities, and problems.

With thought and practice the professional will find that he or she can use virtually every interaction with parents to help achieve these goals. Special behaviors are particularly effective in bringing about positive change in people. The first, the most critical, and the most necessary behavior is attending, which is more than a special kind of listening. This behavior involves a kind of receptive communication that parents can see as well as feel. It involves the professional showing by body language that he or she feels an open receptiveness in being with the other person. It involves the professional establishing and maintaining eye contact that lets the parent know that he or she is attending to him or her. It involves a relaxed yet concentrated involvement with the other person. And finally, the behavior involves the professional sending nonverbal signals which tell the parent that he or she is a person who is interested and can be trusted and who is prepared to really listen.

The professional can communicate at a nonverbal level his or her feelings that parents are people who have valuable information, abilities, and expertise which are important in working with their child. When a study was conducted among parents of handicapped children to determine the reasons for the selection of their physician, the findings showed that the most important factor was a feeling of status of individual personality imparted to them by the physician. Whichever physician made the parent feel important, and
listened to and accepted him or her as a human being, not simply as a conveyer of a child for diagnosis or treatment, received the trust, confidence, and continued involvement of that parent. The research showed that parents may be impressed with the medical degree and reputation of specialists, but they tend to go to the professional who is more empathetic. The research also indicated that parents are much more willing to involve themselves and their child with an attentive, listening professional, and with the counsel he or she offers.

The physical things the professional does lets the parents know that he or she is ready to be with them and to focus on them. To these physical actions the professional must add special ways of listening. Some guidelines for effective, active listening are as follows:

1. Focus on the parent. Pay attention to him or her. Do not be too anxious to tell him or her what he or she is doing wrong. Try to understand the parent's meaning and feelings.
2. Let the parent know that he or she is understood. This attitude promotes a mutual feeling of understanding.
3. Do not make quick judgments. Weigh what the parent is trying to say.
4. Try to accept the world as the parent sees it. This is what people-helpers call empathy, or experiencing another person's world as he or she feels it. Whether or not you agree is not important, but it is important to acknowledge your understanding of what the parent is expressing.

These guidelines for interacting effectively with parents are really more than techniques that can be tacked onto one's repertoire of skills for use at an appropriate time. The professional should think about his or her relationship with parents in a certain way. Some professionals seem to work most comfortably from the position of an expert or an authority. However, research and experience has established that the most meaningful parental involvement and change is fostered through a parent-professional dialogue that stresses equality and acceptance of each other as people. The best approach to parents is as colleagues rather than topdog-underdog. The parent and professional should communicate in their attitudes. Although the professional may have a high level of expertise, the parent knows more about his or her child's needs, feelings, reactions to success and failure, and strengths and weaknesses. Both the professional and parent are responsible for the child's social, emotional, and educational growth, and are interested in his or her welfare and progress. Together, as colleagues on a team, they can work to achieve these goals.

The mutual sharing of information happens more often when the professional makes an effort to listen to the parents. The parents are more willing to listen to what the professional has to say when they know that he or she cares. The professional learns as he or she listens that people in families are different and need different things. Parents may need special help because of cultural differences or because of special family situations. As the professional actively listens, he or she can make better judgments in regard to ways of assisting the parents accomplish goals for helping their children.

Roles of the Professional

In thinking about observing and participating in interactions between helping professionals and parents, I have developed an informal model to accomplish these goals—a frame of reference for thinking about frequently used and helpful intervention procedures. The following are ways of conceptualizing the parent relationships of counselors and of other professionals who have training and expertise other than counseling.

My model has three roles that the professional can use in his or her helping relationship with the families. These roles are (1) information giver; (2) problem-solving helper; and (3) feeling facilitator.

Information Giver

The information giver role acknowledges the importance of the professional sharing his or her special knowledge and skills with the parents. This role is a legitimate activity, even with the emphasis on active listening. However, the information, advice, or orders given out usually are not taken. I recently read that only 30 percent of all prescription medicine is actually taken by parents, even though they were motivated to see a doctor to get the medicine and pay for it. Just giving people information and telling them what to do is not enough. And giving them orders is even worse. Parents need to learn many things from the professional, and the more the professional can involve himself or herself in mutual information sharing sessions, the more change will occur in parents' behavior.

Problem-Solving Helper

Often, beginners in people-helping answer questions too quickly. Time and self-evaluation are
needed to recognize that quick answers really do not help and that another approach is often more successful. That approach is the second role that people-helpers use—the problem-solving helper.

Toilet training is a good example of a problem that is encountered most frequently by the parent. Most professionals could quickly give a list of steps for toilet training steps that make sense, that are logical, and that have worked in the past. I have had some problems with that approach, however. First, maybe half of the parents suddenly developed that well-known psychological phenomenon known as “yes, but.” “Yes, but I tried that and it doesn’t work.” “Yes, but my child won’t do that.” “Yes, but I work and don’t have time,” “Yes, but it is difficult to cure.” The other half of the parents usually responded with “Yes, I’ll try it.” But they returned in a week, and, sometimes with almost a grin, would say, “I did everything you suggested and it didn’t work.”

The problem-solver helper must respond differently in this situation. The professional must use his or her active listening abilities to help parents work through their own solutions. He or she must ask them clarifying questions about what has worked, what the parents feel is feasible in their particular family, and what methods might work in with their beliefs and child rearing techniques. This approach really is teaching the parents a style or method of solving this and other problems.

Sometimes problem-solving requires specific information or answers. The ideal situation is when the parent learns to ask for appropriate information to help him or her formulate his or her own answers. This can be a good time to teach some general principles of child development and learning, like positive reinforcement and consistency, and the special needs of their child, and to help parents learn to apply the principles in their own way in their own situation. In this way, the professional supports and encourages parents to feel comfortable working through their own solutions. Psychologists also know that individuals are much more committed to making solutions work if they are actively involved in finding their own answers. Furthermore, the professional has a chance to teach important principles that the parents can begin to apply to other problem situations.

Feeling Facilitator

The third facet of the professional’s role in working with parents is that of feeling facilitator. Many parents have few resources to help them deal with the stresses they feel. Active listening—giving a feeling that you’re hearing, understanding, accepting, not judging—is a special quality that can be used to effect positive change in parents and, thus, in the whole family unit.

The help and support given to families in dealing with feelings and emotions is important. Alan Ross, in his book *The Exceptional Child in the Family*, points out that the presence or absence of characteristics such as acceptance, understanding, and warmth is very often the difference between a professional who is really helpful and one who causes a great deal of misery and confusion during the course of his or her contact with the family. The professional provides the best possible support for parents to grow in healthy ways as he or she communicates his or her understanding and acceptance of parents and their feeling reactions to their child and his or her problems.

Summary

This paper is about counseling parents, about our continuing growth in using human ways of interacting with people who have special needs and special problems, and about our commitment to have positive effects on children’s environments by helping their parents cope more effectively. Pearl Buck in her book *The Child Who Never Grew* presents a dramatic portrayal of her feelings and her growth as she faced the reality of her handicapped child. She wrote of feelings the professional encounters in the families he or she sees—feelings he or she can influence so tremendously.

To learn how to bear the inevitable sorrow is not easily done. I can look back on it now, the lesson learned, and see the steps; but when I was taking them they were hard indeed, each apparently insurmountable. For in addition to the practical problem of how to protect the child’s life, there is the problem of one’s own self in misery. All the brightness of life is gone, all the pride of parenthood. . . . Death would be far easier to bear, far death is final. What was is no more. How often did I cry out in my heart that it would be better if my child died? If that shocks you who have not known, it will not shock those who do know.

The professional accepts parents’ feelings and, by accepting and understanding, can help them move to more comfortable places.

Pearl Buck did move and did grow. In later correspondence to other parents, she revealed a change in her thinking and an acceptance of her handicapped child.

Be proud of your child, accept him or her as he or she is and do not heed the words and stares of those who do
not know better. The child has a meaning for you and for all children. You will find a joy you cannot now suspect in fulfilling his or her life for and with him or her. Lift up your head and go your appointed way.

References


Optimal educational programming for deaf-blind children cannot be realized until the children are in a state of health which enables them to participate effectively in such programming. Children who are chronically ill with heart disease, kidney disorders, or asthma may be too weak to participate in routine program activities. Similarly, children with incompletely managed hearing and vision problems need help from many disciplines to realize the optimal use of their residual hearing and vision.

**Health Professionals and the Interdisciplinary Team**

The maintenance of optimal health for multi-handicapped, deaf-blind children requires an effective working partnership among health professionals, parents, and teachers. Some of the most important qualities in that partnership are trust in the competence of other professionals on the interdisciplinary team, mutual respect for the contributions of each profession, an attitude which promotes the welfare of the child over that of any individual discipline or governmental bureaucracy, and open and free communications between disciplines. Such an interdisciplinary relationship may be viewed in the scheme below.

In this scheme the child and his or her needs are central to the purpose of the program and the interaction of each discipline. Therefore, when the question arises "How do we proceed now, given the present problem?" the answer should always be given in the context of whatever is in the best interest of the child.

The physician's role on the interdisciplinary team is often crucial and one which most are reluctant to fill. Many skilled physicians have little training or experience in the special needs of the blind, deaf, or multihandicapped retarded child and are unaware of the resources available in the community to help such children. Their advice is often based on out-of-date information or personal bias about what is best for such children. The weight of their opinion has too often been sufficient to persuade parents of young handicapped children that placement in custodial care institutions is in the best interest of the child and the family, when neither of these outcomes is in fact true. Children should never be placed in a public residential facility for the mentally retarded until habilitation has been attempted by the members of an experienced interdisciplinary team.

Physicians too often treat acute illnesses in the multihandicapped child without giving adequate attention to his or her chronic care needs. The family of that child requires extra time from the doctor to learn as clearly as possible the following:

1. Child's etiologic diagnosis (cause of the chronic disability)
2. Medical implications of the diagnosis
3. Projected plan of management
4. Possible complications of treatment
5. Expected outcome of treatment
6. Frequency of follow-up

Crucial in this management plan is the identification of a primary care physician, generally a pediatrician, who is prepared to be the child's doctor and advocate. He or she will evaluate, coordinate, synthesize, and interpret medical information for parents and teachers, and share aspects of the child's medical record with those persons who have a need to know.

Parents and teachers must understand that not all physicians can, nor should they have to, fill this
role for the deaf-blind child. On the other hand, a small number of physicians who have the appropriate set of skills and proper personal attitudes to fill this role are usually available. Their friendship should be cultivated, for their support will be of great value in the programs.

**Guidelines for Management of Medical Problems in the Classroom**

What follows should not be interpreted as a cookbook for management of medical emergencies. The discussion deals with problems manifested in certain organ systems. It is no substitute for prompt medical attention provided by skilled nurses and physicians for children, or appropriate inservice sessions for teachers.

**Neurology**

Effective management of seizure disorders requires good communication between the physician and the teacher. The classroom teacher should report to the family and/or physician any apparent increase in frequency or severity of seizures in children with epilepsy. Such changes may be an indication that the child has stopped taking his or her medication, has outgrown his or her present dosage, or has a new medical condition which has lowered his or her seizure threshold. Physicians must have adequate information on the effectiveness of antiseizure medication; if the child becomes too drowsy or becomes hyperactive (a common side effect of barbiturates in children with brain injuries), the matter should be discussed promptly with the physician.

If a child has a grand mal seizure in the classroom, the teacher should not panic or try to force a stick into his or her mouth. This action may dislodge a tooth which may then be aspirated. The child's collar should be loosened and head hyperextended so that the airway is not obstructed. The appropriate medical personnel should be notified. Any vigorous movements of the arms and legs during the seizure are not harmful.

An EEG provides information of limited usefulness. Not every brain-injured child needs one, especially in the absence of seizures; and not all brain-injured or mentally retarded children require a neurological examination. These are issues which often can be adequately dealt with by experienced pediatricians.

Behavior disorders can interfere with the educational progress of deaf-blind children. Self-stimulatory behavior, self-abuse, hyperactivity, or abuse to others is well known to teachers and parents of deaf-blind children and may be dealt with by using behavior modification or other psychological intervention. A useful adjunct to such intervention may be the use of appropriate doses of psychopharmacological agents. Some children respond to drugs such as Thorazine, Mellaril, and Benadryl, as well as others, in that they then become amenable to other treatments. Although the stimulant class of drugs is occasionally useful (Ritalin, Dexedrine), special care must be used because these drugs sometimes make the target behavior worse. Cooperation between the physician and the teacher is important, because the type and dose of drug is often used empirically, and the physician needs frequent feedback about the effectiveness or untoward side effects when such drugs are used.

**Cardiac Disorders**

Most children with heart murmurs have what are called "innocent murmurs," in which the noise the heart makes is not associated with any heart defect. Teachers who have children in their classroom with known serious heart disease should be informed of the management plan for these children, including the use of oxygen during cyanotic spells, if it is prescribed by the heart specialist. The presence of a murmur does not indicate that a child cannot participate in all classroom activities, but one must individualize and review each child's special needs with his or her physician and parent.

**Ear Problems**

Special emphasis should be directed at the early identification and treatment of deaf-blind children with ear infections. The last thing a child with partial sensorineural hearing loss needs is an ear infection which renders him or her functionally deaf. Teachers who determine that a deaf-blind child has suddenly become more inattentive, or has lost some hearing or speech skills, should refer the child for medical evaluation for a possible ear infection.

**Eye Problems**

Teachers should work at trying to extinguish behaviors which endanger any residual vision in self-abusive deaf-blind children. Frequent eye poking or other eye trauma can lead to bleeding within the eye, which in turn can result in total loss of functional vision. Deaf-blind children require frequent and periodic reevaluation of their vision by ophthalmologists and/or optometrists, with an appropriate prescription for corrective lenses.
Orthopedic Problems

Deaf-blind children with orthopedic deformities require the well-coordinated services of an interdisciplinary team which should include a physiatrist, orthopedist, and physical therapist. Well-planned and timed orthopedic surgery preceded and followed by physical therapy, and the provision of assistive devices, has enabled many deaf-blind children to develop new mobility skills. These skills in turn can lead to access to educational programs previously denied to them, to the development of new skills in activities of daily living, or to a broader touch with their environment.

Dental Care

Dental care is probably the most neglected area in health care for multihandicapped children. Most surveys of this population reveal that an overwhelming majority have unmet or unrecognized dental needs. Dental services, especially the preventive aspects, must be an integral part of the interdisciplinary program to prevent chronic dental infection, pain, loss of teeth, and other preventable conditions which have such a major impact on speech development, feeding, and nutrition programs.
Teachers should use a method or approach that they feel comfortable with and have adapted to meet the needs of the individual being taught. The deaf-blind child can be taught a specific task if it is broken down into sequential developmental steps which are introduced one step at a time.

Developmental progression is affected by a great many factors, including the principles of motor development. Two major factors of great importance are maturation, as it is related to time and aging changes, and experience, which is personal and closely associated with the child’s environment. The teacher is responsible for planning a wide range of experiences within the child’s environment to elicit learning and development (Thomas, 1975).

The two growth principles that govern motor development are cephalocaudal, which is developmental progression from head to foot, and proximal-distal, which is growth from the midline (center) of the body outward (Thomas, 1975). With these principles in mind, it is easier to understand that movement develops from gross mass movements to more refined gross movements and then to fine coordinated movement patterns, abilities, and skills.

**Sequential Development Steps**

As the child progresses through the developmental age levels, some skills remain constant while others become more refined. Sometimes the child reverts to earlier behaviors, which is thought to be a purposeful form of regression that allows the child the opportunity to strengthen his or her acquired skills in preparation for moving to the next sequential step (Thomas, 1975). Steps in the sequential development of fine motor skills are as follows:

<table>
<thead>
<tr>
<th>0-3 months</th>
<th>3-6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflex grasp</td>
<td>Holds small objects placed in hand</td>
</tr>
<tr>
<td></td>
<td>Palmar grasp</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hands engage at midline</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6-9 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfers object hand to hand</td>
</tr>
<tr>
<td>Uses palm-finger grasp</td>
</tr>
<tr>
<td>Reaches for nearby objects on sight</td>
</tr>
<tr>
<td>Brings objects to mouth (7 months)</td>
</tr>
<tr>
<td>Drops objects (7 months)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9-12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thumb-finger grasp emerging</td>
</tr>
<tr>
<td>Deliberate, coordinated reach for an object</td>
</tr>
<tr>
<td>Crude, deliberate release</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pincer grasp</td>
</tr>
<tr>
<td>Voluntary release</td>
</tr>
<tr>
<td>Brings one block over another</td>
</tr>
<tr>
<td>Pulls pegs one by one from pegboard</td>
</tr>
<tr>
<td>Rolls ball</td>
</tr>
<tr>
<td>Bangs crayon with full-arm action; much lateral movement; raises hand high; often misses paper</td>
</tr>
<tr>
<td>Interested in working movable objects</td>
</tr>
<tr>
<td>Purposefully moves toys from one place to another</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1-1½ year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Places peg in pegboard</td>
</tr>
<tr>
<td>Builds three-block tower</td>
</tr>
<tr>
<td>Turns two or three pages of book at a time</td>
</tr>
<tr>
<td>Dumps pellets responsibly</td>
</tr>
<tr>
<td>Scribbles spontaneously</td>
</tr>
<tr>
<td>Makes a stroke imitatively</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand preference</td>
</tr>
<tr>
<td>Builds five to seven block tower</td>
</tr>
<tr>
<td>Turns doorknob</td>
</tr>
<tr>
<td>Turns pages one at a time</td>
</tr>
<tr>
<td>Throws 3-inch-diameter ball</td>
</tr>
<tr>
<td>Folds paper once, imitatively</td>
</tr>
<tr>
<td>Formboard: adapts to rotation in four trials (3 piece)</td>
</tr>
</tbody>
</table>
Strings 1-inch-diameter beads
Unscrews lids
Unwraps paper from candy
Snips with scissors

2 1/2 years
Builds tower of eight cubes
Formboard: adapts repeatedly to rotated formboard, error
 Throws ball 5 to 7 ft.; poor direction
Holds crayon with fingers
Can carry breakable object

3 years
Builds tower of ten cubes
Imitates bridge (three blocks)
Places ten pellets in bottle (30 seconds)
Adapts to formboard without error

4 years
Places ten pellets in bottle (25 seconds)
Folds and creases paper three times on demonstration
Catches bounced ball

5 years
Uses hand more in catching ball
Some idea of coloring within lines
Puts ten pellets in bottle (20 seconds)

Some suggested sequential fine motor skills are as follows (Ellisville, 1976):

To develop the ability to hold an object:
1. Place objects of varied textures, colors, sizes, shapes, and weights in the hand.
2. Hang mobiles within touching distance of the child. When the child is on the floor, place bright objects within child's visual field and hand reach.
3. As the child begins to hold objects, decrease the size to increase the child's finger strength.

To develop a pincer grasp:
1. Use materials (that is, clay, sand, yarn, tape) to encourage the child to explore using his or her hands and fingers. (Spread fingers in sand and poke finger in clay.)
2. Encourage the child to finger feed food in self-feeding.
3. Use a pegboard, and so forth, with holes for the child to poke and explore with his or her fingers.

To develop a release and continue improving the grasp:
1. Have the child seated at a table and work behind him or her. Place one cube and a container in front of him or her. Have him or her pick up the cube and put it in the container; then place another cube and repeat the task. Decrease assistance as the child's ability increases. Use verbal, visual, and tactile cuing.
2. Using verbal, visual, and tactile cuing, have the child grasp various sizes and textures of objects and then release them in your hand or on the table. Decrease assistance as his or her ability increases.
3. Using verbal, visual, and tactile cuing, have the child grasp and remove large pegs from the pegboard and place the pegs in a container. As his or her ability increases, decrease assistance. (In order to refine his or her skill and ability, decrease the size of the pegs.)

To develop the ability to throw and catch:
1. Sit on the floor with the child between your legs. Using a large ball (6 to 10 inches in diameter), place the child's hands on the ball while using verbal and tactile cuing. Have the child pick up the ball and hold it. Have the child push (roll) the ball; then have him or her catch it. As his or her ability increases, decrease assistance. As his or her ability to catch and push the larger ball increases, decrease the size of the ball. Encourage the child to use any residual vision he or she has.
2. Sit on the floor with the child between your legs. Using a large ball (6 to 10 inches in diameter), place the child's hands on the ball while using verbal and tactile cuing. Place your hands over the child's hands and have him or her throw the ball. As his or her ability increases, decrease assistance. Work on his or her catching by working from behind with your hands over his or her hands. As his or her ability increases in throwing and catching, decrease the size of the ball. (Start with a 10-inch-diameter playground or Nerf ball.)
3. Activities 2 and 3 above can be used with a brightly colored 3- to 4-inch-diameter ball with the teacher across the table from the child.
4. Set up a target (box or trash can) a short distance from the child. Have the child throw at the box. As he or she becomes accurate at this distance, increase the distance.
To develop the ability to purposely manipulate objects:

1. Using 1-inch cubes, make a tower with two or three cubes as an example for the child; then have the child imitate the tower. If he or she will not, use the hand-over-hand technique and assist him or her. As his or her ability increases, decrease assistance until the child can perform the task. Suggestion: you could progress to color matching with a simple tower.

2. Using a similar technique, work with additional block patterns (that is, higher towers of 4, 5, 6, and 8 blocks).

3. Using stiff, thick-paged children's books, begin to teach the child how to turn the pages. Begin by using the hand-over-hand technique and decrease assistance as the child's ability increases.

4. Using a buttoning board with large buttons, begin teaching the child to button and unbutton, using the hand-over-hand technique with the teacher working from behind the child. As the child's ability increases, decrease assistance. Decrease the size of the buttons as the child learns the task.

5. Using an oversized shirt with large buttons, put the shirt on the child and have the child button the buttons. When the child has mastered this task, have him or her button the buttons on his or her shirt.

6. Zipping, unzipping, snapping, unsnapping, hooking, and unhooking can be taught using same procedure as items 4 and 5.

Motor Terms

Since this is the age of accountability, an individualized educational plan with ongoing assessment must be provided for each child. The strengths and weaknesses or functioning level of a child must be known to provide such a plan. In addition, an understanding of motor terms is needed. This terminology is found throughout the literature in the various areas of development. Since there is such an overlap of the areas of development, I have prepared the following list of terms from several sources with what I hope will be applicable and workable definitions:

Motor development The growth and elaboration of the nervous and muscular systems of an individual.

Gross motor skills A movement or series of movements involving the large muscle groups.

The movements require a high degree of precision for the accomplishment of a specific end.

Fine motor skills—A movement or series of movements involving the smaller muscles of the extremities. The movements require a high degree of precision for the accomplishment of a specific end. These are often manipulative movements which are related to the development of eye-hand coordination.

Skill development—A particular type of body movement which is dependent on a certain degree of muscular control, and which may be learned or improved through physical repetition.

Motor pattern—The movement characteristics in the performance of physical skill.

Locomotor—Patterns or skills used to propel the body through space. Includes crawling, rolling, walking, running, jumping, hopping, and related tasks.

Motor learning—Apparently permanent change in motor performance brought about through practice and excludes change from maturation, drugs, and the like.

Body image—The body scheme or total sensory impression of one's own body and its relationship to space and the world around it. Self-concept or self-picture of one's body in space.

Object-concept—An awareness of objects in space as entities apart from oneself. Object-concept is a part of body image.

Laterality—An internal awareness of the two sides of the body and their resulting difference. Awareness and distinction between left and right sides of the body and of left and right within one's own body.

Directionality—An awareness of and distinction between and among left, right, up, down, front, back, and so forth, in the world around one. Awareness of directional relationships in space. Directionality depends upon laterality.

Perceptual motor—The inseparable integration of perceptual and motor functions or activities as one interdependent and interrelated behavioral area.

Motor planning—The development of a movement pattern performed for the accomplishment of some external purpose or specific end.

Kinesthetic sense The muscular sense of movement or position of the body or a part of the body.

Sensory input The process of organizing the environmental stimuli.

Motor output The integration of environmental stimuli on the basis of past experiences and
present circumstances and reaching in a way which is meaningful to the individual.  

**Maturation**—The orderly change in development based upon a necessary aging or temporal element.  

**Experience**—All environmental interactions, including specific movement training an individual may receive.  

Fine motor skills programming for deaf-blind and multihandicapped children in the classroom must provide a structured routine and consistency of routine. With all of the emphasis on a full continuum of services, it is most important that there be a carryover from the classroom to the home. Program objectives must be developed that will aid the child in adapting to his or her environment and in reaching his or her maximum potential.

---

**References**


The purpose of this paper is to review early educational services to deaf-blind and multihandicapped infants. In it I discuss (1) a hospital-based preschool for multihandicapped children; (2) a program for hospitalized handicapped children; and (3) a home-training program for deaf-blind and multihandicapped children. I hope the latter will be helpful to public health nurses who are often responsible for the identification, coordination, and delivery of service to the handicapped children on their respective islands.

Background Information

The developmental disabilities center at The Roosevelt Hospital evolved from a rubella research program which began at New York University Medical Center in 1962. An interdisciplinary rubella project was created in 1964 in response to the epidemic. The purpose of the project was to facilitate research on rubella vaccines and to deliver medical services to the hundreds of infants referred to the research laboratory. More than 600 children with congenital rubella have been evaluated and followed longitudinally since 1965. In 1967, after the rubella project identified 60 two- and three-year-old children who were multihandicapped and receiving no educational services, a rubella nursery was established at Bellevue Hospital. The nursery added a strong educational component to a program that originated in a laboratory.

In 1973 the rubella project was moved to The Roosevelt Hospital, an integral component of the Department of Pediatrics of the College of Physicians and Surgeons of Columbia University. The extension of service to patients who could profit from care similar to that offered children with congenital rubella led to a broad-based project serving handicapped and multihandicapped infants and children without regard to etiology. In 1975 the rubella project was designated as a developmental disability center by the university. In addition to an active laboratory, which continues to function as a center for research on the epidemiology, clinical course, viral immunology and management of congenital rubella, and laboratory and community evaluation of rubella vaccines, the developmental disability center includes a developmental disabilities section, a child-neurology section, and a child development section of which the expanded preschool for multihandicapped children, formerly known as the rubella nursery, is a component.

Preschool for Multihandicapped Children

The preschool was created in 1967 because of the unmet needs of rubella-damaged children. The hypothesis for intervening was that, with intervention, severely multihandicapped children could learn from complex interdisciplinary special education techniques. Presently accepted concepts of child development, as they apply to deaf-blind and multihandicapped infants and children, reinforce this hypothesis and are stated as follows:

1. An infant born biologically intact can develop to full genetic potential if his or her environment is normal-experiential.
2. An infant born biologically intact will demonstrate developmental attrition or failure to achieve his or her genetic potential if he or she is environmentally deprived.
3. An infant born with biologic deficits, such as deafness, blindness, brain injury, or some combination thereof, is at risk of developmental attrition equal to or greater than the biologic insult (Appell, 1977).

The rationale for intervention programs for children with such deficits is the belief that compensatory or alternative experiences may prevent or minimize attrition. This belief is based on decades of laboratory and clinical observation. Unfortunately, none of these data as yet provide documentation of the impact of early intervention on life outcome of the deaf-blind and multihandicapped child and his or her family (Appell, 1977).

Despite the lack of documentation, the research data on deprivation, parent-infant interaction and
relationships, and the role of the environment to the child's development more than justify the need for early detection, intervention, and education (State of the Art, 1977).

Philosophy and Program Components

The philosophy and program components of the preschool reflect some of the aforementioned beliefs. The program is not only geared to the child in his or her environment, but is also adapted to his or her specific needs and developmental status at the time of intervention. The program recognizes that the diagnosis of the severely handicapped child is an ongoing process that cannot be separated from treatment and that treatment cannot be separated from the home environment if carry-over is to have real impact on the life-style of the multihandicapped child. The educational program is coordinated with social and medical services and is hospital-based to effect the delivery of better and more comprehensive care. However, as those in the field know, multihandicapped children often have complex medical needs, including additional input from ancillary personnel such as audiologists, physical and occupational therapists, optometrists, nutritionists, and so forth. Many appointments need to be ongoing, such as audiological evaluation. The coordination of all these services requires time, skill, and perseverance. The public health nurses play an invaluable role in helping parents to navigate the service delivery system. Even when services are coordinated under one roof, parents still need a person whose role it is to collate, translate, and follow through on recommendations, medication, referrals, and other appointments. Therefore, each child enrolled in the preschool has his or her own public health nurse or family health worker who attempts to coordinate medical and other appointments with the child's preschool program, so that a teacher can accompany the parent(s) to appointments and or specialty clinics and/or the parents are saved from making endless trips back and forth from hospital to home.

The children who attend the preschool range in age from birth to six years; however, older children not yet in a suitable long-range school setting continue to be eligible for service. Emphasis is placed on the earliest possible intake of the very young child. Eligibility for the program is based upon suspicion of visual and auditory impairment and the presence of conditions such as cerebral dysfunction, behavioral disturbance: neuromuscular disorders, and orthopedic diseases. The initial determination of the clinical status of each child is accomplished by the multidisciplinary developmental disability center staff. A member of the educational team is present during the initial pediatric examination to administer the developmental/educational evaluation. A staff conference is subsequently held during which all disciplines determine jointly whether additional assessment is necessary prior to either immediate referral to a facility within the community or to the preschool. Staffing conferences are not unique, but we have found that immediate minstaffings reduce the time lag between evaluation and referral for service, which can sometimes be a lengthy process.

The staff of the preschool, since its inception, has been interdisciplinary, with teachers and assistant teachers representing discrete subspecialties within special education. The rationale for this decision is based on the needs of the children to be served. Multihandicapped infants and children have such a diversity of needs that professional knowledge and skills need to be pooled to provide the prescribed services. Also, since 1969, the preschool has employed a full-time pediatric occupational therapist with experience in the area of gross and fine motor development. Although it was unorthodox in 1969 and commonplace in 1977, parents are also considered as part of the preschool staff. Our goal has been to have visitors not be able to distinguish parents from the staff by the end of the year. A full-time social worker has also been a member of the staff for the last five years. Group meetings and individual counseling, as needed, provide emotional support to parents of handicapped children. Such parents must have an outlet through which feelings about their children may be ventilated. This practice, in addition to learning specific skills and techniques, helps to increase feelings of self-confidence and competence.

Preschool Curriculum

The preschool curriculum has been and I hope will continue to be an evolving compendium of activities for handicapped children. Curriculum becomes richer and more facilitative as behavioral scientists uncover the processes underlying the nature of learning and as we learn more about how infants learn to learn. Three major philosophical models predominate in early childhood education at the present time: (1) the behavior modification approach; (2) the normal-developmental approach; and (3) the cognitive developmental approach or the Piagetian model (Anastasiow, 1975). Early educational programs for the deaf-blind and multi-handicapped had to consider the severity of the
child's handicaps and the wide range of clinical and socioemotional differences when planning curriculum. Therefore, exclusive reliance on any one of these approaches ignores individual differences. An approach that incorporates elements from each of these child development models serves as the basis for planning the educational program for the children enrolled in the preschool. The curriculum contains elements of all three models, although the normal-developmental model predominates. 

The Piagetian model is essential conceptually to understand the hierarchical stages involved in learning. However, a great deal of Piagetian programming is lost on the severely handicapped child. We have had success recently in integrating some of the object-permanence tasks on the Hunt-Uzgiris Assessment Scale into the program. Aluminum foil appears to be a compelling material, and we have covered graded rings and other objects with foil to encourage searching behavior. Behavior modification or a highly structured contingency reinforcement program is difficult to transfer to the home environment of the preschool and older child. However, behavior theory has been integrated into our program and is used successfully in both the preschool and the home to extinguish certain self-abusive behaviors. These behaviors are so noxious to parents that, even in chaotic home circumstances, behavior charting and contingency reinforcement has been implemented. This is intrinsic to the success of the program because the child spends many more hours at home than in the preschool. Self-abusive behavior is easier to extinguish in children under three years of age than when older. Support and reinforcement to the parents to ignore this often attention-seeking behavior in this age group is crucial. It is very difficult to turn one's back on a child who is hitting himself, but once parents understand the cause-effect relationship in play, consistent follow-through ensues.

I would like to share a recent experience that I had with parents who were attending the preschool. Parents of handicapped children often lose sight of and become impatient with their child's slow rate of demonstrable progress. A simple developmental checklist was devised in which milestones were listed sequentially, but the age of attainment was omitted to remove the stigmata attached to judging or labeling the child. The parents were asked to check whether their child performed a task consistently or sometimes. Upon completion of the checklist, the universal comment was "Of course, my child has made progress! I didn't realize that before you can walk, you have to stand independently first." The checklist gave the parents the opportunity to regain perspective and to reinforce the concept that children move through ordered stages. This is not unique to parents; professional staff have the same need to reality test. Videotaping the children on a three- to six-month basis helps to gain or regain perspective. If videotape equipment is not available, still photography is an alternative.

Summary

In summary, the preschool program is structured so that activities follow a normal-developmental sequence and are teacher-planned and imposed on the children. However, do not interpret this to mean that the program is rigid and procrustean. The individual teaching styles, training, and personalities of the teachers and therapists, in addition to a program philosophy that allows for trial and error, contribute to an open-ended curriculum that contains an ever-increasing repertoire of activities.

Program Activities

Program activities for deaf-blind and multihandicapped children must, by necessity, compensate for overwhelming sensory deprivation. The role that vision and audition play in learning have to be assumed by taction and kinesthetic feedback. The environment of the child should, therefore, be rich in objects to feel and touch, smell and taste, see and hear. The converse is so often true because parents, relatives, and well-meaning friends presume that the deaf-blind child cannot benefit from these experiences. A major and initial responsibility of the program is to encourage and help the parents to provide an environment that is rich instead of sterile. It does not require a large capital outlay, but creative and constructive use of the natural environment. A toy can be constructed from almost anything, including paper plates and cups for mobiles, to the use of pots, pans, and spoons for musical instruments. The bathtub or beach is a wonderful teaching environment by the very nature of the natural sensory stimulation they provide.

Program Content

Program content centers around four major areas in child development: language, motor, adaptive, and affective behaviors. However, program emphasis differs with the needs of the individual child. In addition, many activities overlap and are continuous with each other. It is very
difficult to separate language as an entity from activities designed to stimulate sensorimotor awareness. A point I would like to emphasize about deaf-blind children is the need to constantly challenge and stimulate visual and auditory modalities. Many multihandicapped children do not make maximum use of their residual hearing or vision. They should be encouraged to track and reach for objects so that they learn to see and to reach out and interact with objects in the environment. Also, just as the normal infant learns to hear, the multihandicapped child needs to be taught to "tune in" so that he or she can attach meaning to environmental sounds, including words. Auditory training is important and must be repetitive to be effective. This is a good point at which to discuss two issues: amplification and speech. A direct relationship is apparent between the child's use of and adjustment to amplification and corrective lenses with parental acceptance of these appliances. This, of course, relates to the more complex issue of adjustment to and acceptance of the handicapped child. Obviously, eyeglasses and hearing aids become visible when the infant is too large to transport in a baby carriage. Therefore, substantial, continuous, and prolonged effort is necessary on the part of the teaching staff to help the family to accept the child's disabilities and to accomplish acceptance of the appliances. However, even with optimal parental support, a large proportion of the deaf-blind and multihandicapped children enrolled in the program have not and do not readily accept these devices. Even with perseverance and cooperation, we have failed completely to get some children to accept just eyeglass frames.

Early amplification of sound for multihandicapped children is problematical because most of the children are difficult to test, and a reliable audiogram is difficult to obtain. In fact, an accurate, pure-tone audiogram is almost impossible to obtain from a deaf-blind child early on. Nonetheless, the use of amplification should be explored at a trial on experimental basis. This requires careful coordination and cooperation among the teaching staff, parents, and the audiologist. Selection of appropriate hearing aids is a process that can take as long as four to five years to accomplish.

Most of the experiences and activities incorporated into the preschool program are geared to the sensorimotor period of development. In addition to auditory and visual stimulation and motor training, emphasis is placed on motoric exploration of the environment. The major means of gathering and processing information uses tactual and kinesthetic feedback. Sensory input through these channels is the nucleus of media experiences. The major source of materials for these activities is the neighborhood supermarket. Some examples of these experiences include finger painting with different flavored puddings and instant cereals. Texture may be added to the basic equipment by throwing in some raisins, chocolate chips, or shredded coconut, while olfaction may be stimulated by adding spices. Jello not only provides a variety of tactual experiences but also makes good building blocks when frozen. Bananas and oranges may be peeled, sliced, squeezed, mashed, and eaten.

Activities of Daily Living (ADL) are integrated experientially into every facet of the preschool program. The child's mastery of skills such as feeding, washing, and dressing enables him or her to be more self-sufficient and allows him or her to be integrated into the family unit with much less strain.

Nutrition and diet are integral components of the program. Because the multihandicapped child often has difficulty with eating, his or her nutritional intake is generally a problem. Failure to thrive is a common clinical manifestation in the patient population of the inner-city ghettos. Lunch is included as part of the program not only to demonstrate feeding techniques but also to introduce the components of a well-balanced diet. In this way, the multihandicapped child and his or her entire family may benefit from the experience.

Staff Training

An aspect of the program that I would like to discuss before summarizing this section involves the training of the professional staff. The developmental disability center provides interdisciplinary training in mental retardation and other developmental disabilities as a primary function of the program. At the present time, three full-time pediatric fellows in the care of handicapped children, pediatric residents, medical students, and undergraduate and graduate nursing students rotate through the preschool as part of their training program. This relationship not only provides a sophisticated level of medical care to the children but also presents a unique opportunity to train medical personnel in the special problems of the multihandicapped child and the functioning of an education-oriented intervention program.
Summary

To summarize this section, the expected outcomes of the preschool program include (1) the reduction in the detrimental time lag between evaluation and service for the infant, older child, and the family; (2) the coordination of medical and educational service; (3) the follow-through on recommendations made by team members; and (4) the continuation of supportive services as long as they are needed by the child and family. As a result of the increased parent-child interaction, the parent is expected to be better able to serve as the child's advocate once he or she enters the mainstream of the special education delivery system.

Program for Hospitalized Handicapped Children

Hospitalization for normal children is often a traumatic and isolating experience. The complex medical needs of severely handicapped infants and children often require frequent hospitalization for surgery and illness, which presents two problems: (1) the isolation of the child and his parents while in the hospital; and (2) the failure to refer the child and parents to an educational or therapeutic program once the medical crisis has ended.

Very few hospitals have the staff to stimulate hospitalized handicapped children. In addition, most hospital personnel are not comfortable dealing with the handicapped other than on a medical basis. Handicapped children are in many instances excluded from pediatric recreation programs and left to fend for themselves in their rooms. Administrative reorganization in our hospital four years ago allowed us to change the orientation and direction of the playroom program. A special educator, with background in normal child development and education, was hired as the playroom teacher. This immediately meant that the handicapped infants and children would be included in activities. Even if the child or children were incapable of active participation, they were no longer left to self-stimulate in the isolation of their rooms. In addition, an individual educational plan was devised and placed in the child's medical chart, where it remained with daily progress notes for the duration of hospitalization.

The addition to the pediatric inpatient staff of a member trained to work with the handicapped had an impact by the end of the first six months. Staff began to spontaneously implement feeding and sensorimotor stimulation programs. In fact, some infants and children were brought to the nurse's station to spend the day to prevent further isolation. Parents no longer felt isolated, because they now had someone who they could relate to and who they knew was interested in their child and the management of his or her total welfare. When a health education component was added to the playroom program two years ago, the handicapped who could benefit from it were automatically included. Preparation for surgery is now accomplished with backup support provided by the preschool staff. The assistant teacher in the preschool, herself the mother of a profoundly deaf child, explains the presurgery and postsurgery procedures to all the deaf children admitted to the hospital. She often takes them to see the operating and recovery rooms. The result, of course, is a less fearful and anxious patient. One deaf child was terrified that she would never walk again because she had misunderstood that surgery was for her heart and not her knee.

Before the addition of the special educator to the pediatric inpatient staff, referral to an educational program within the community was a serendipitous event. This no longer occurs because the handicapped children are now automatically included in the weekly social service rounds in which discharge and referral plans are routinely made for all children on the pediatric floor.

Home Training Program

Home training is an important component of the preschool program. I left the description of this component for last so that it can be described as an element or ingredient within a total program. This is in contrast to programs in which home training is the entire program. The Portage Project is a successful example of the latter. In our early efforts, we found that this wasn't a satisfactory model for our population. I do not have a detailed working knowledge of the Portage program, but from my limited experience, I believe that the population it serves is different from that of the urban inner-city. One-parent households with severely multihandicapped children make up a considerable portion of our caseload. Because we have not been successful with a solo or free-standing home training program, we developed a combined model in which the home training team is an integral component of the hospital-based program, tailor-made for suitability to the family's real-life circumstances. Most of the children enrolled in home training attend the preschool concurrently. However, one to two families a year cannot attend the hospital-based program for either health or economic reasons and receive home training exclusively. The home trainers also
follow their cases during hospitalizations and work with the playroom teachers to ensure carry-over from the pediatric ward to the home.

The home trainers for our program have background and training in both health and special education and are licensed as health aides by the New York City Department of Health. This dual skill is important, because the families selected for home training all need assistance with follow-through on medical and educational recommendations. These families are not necessarily indigent, ignorant, or incapable, but they do need added supportive services, very often after hospitalization of one of their members.

The home trainers work as a pair for reasons of safety. They travel throughout the boroughs of New York City in a minibus that was donated to the program. A kit of supplies and equipment which they use during the week is kept on the bus. The curriculum for the home training program is as formalized and individualized as that of the preschool. The team meets once a week with the preschool staff, playroom teachers, and medical staff to exchange information and for feedback.

The home training, playroom, and preschool do not function in isolation, but as components of a program that attempts to deliver a continuum of medical, social, and educational services. The educational program is hospital-based, because this is where the severely handicapped child’s needs first become apparent and where, during the early months of life, vital elements of the service delivery system are obtained.

References


Therapy Techniques with Deaf-Blind Children

Betty Scanlan
Physical and Occupational Therapy Supervisor
West Suburban Association for the Hearing, Orthopedically, and Visually Impaired
Lombard, Illinois

This paper deals with both the occupational therapist and the physical therapist and what they do, the similarities and differences in their techniques, and how their services can be obtained. A great deal of confusion exists in people's minds as to what these professionals do and what the differences are in their services. This confusion stems from the fact that there are many overlapping areas in their services, especially in working with children in rural areas where only one or the other may be available.

Occupational and Physical Therapist

Both the occupational therapist and the physical therapist work on improving muscle strength, increasing range of motion, encouraging normal motor development, and increasing physical endurance. A major difference between these two professionals is in the use of treatment techniques. The physical therapist uses hydrotherapy, heat, massage, ultrasound, and exercise to improve muscle function and coordination. The occupational therapist uses active involvement of the patient in specially designed tasks and activities to improve muscle function and coordination. These activities are usually in the form of play activities with children. The occupational therapist also is involved in helping the patient use his or her muscle function and coordination to meet the demands of daily activities. These daily living skills include feeding, dressing, and preparing for or meeting the demands of a school or work situation. School demands include such skills as fine motor functioning and perceptual motor abilities. Physical therapists are more often involved in ambulation and gait training, while occupational therapists are more often involved in making splints and adaptive devices such as built-up handle spoons for children with a weak grasping ability.

Both professions have national organizations that maintain registries of the membership. Persons interested in obtaining information on therapists in their areas can write directly to the following organizations:

American Occupational Therapy Association
6000 Executive Blvd.
Rockville, Maryland 20852
American Physical Therapy Association
1156 15th St., N. W.
Washington, D. C. 20005

Assessment and Screening

The deaf-blind child's motor development problems must be looked at in terms of etiology or causes. With rubella children several characteristic motor problems are usually obvious. These children are often hypotonic, or they do not have normal muscle tone. They may also exhibit hypermobility of the joints, or they may be able to bend more than normal at the joints. For example, most people are only able to extend their wrists about 90 degrees; however, these children can extend their wrists beyond that degree of mobility.

Causes of Deafness and Blindness

Other frequent causes of deafness and blindness are birth trauma and meningitis. These children often have the additional handicap of cerebral palsy (CP), which is not a disease or an illness but a physical disability caused by brain damage of a nonprogressive nature. By definition the damage occurs before birth, during birth, or in early infancy. The damage affects the immature brain during the process of development. Cerebral palsy is not a weakness of the muscles but a lack of development of normal patterns. It is an inability to provide a normal balance between inhibition and facilitation; such balance is necessary for normal tone and movement. In normal movements a person has a balance between what are called the inhibitory and facilitary muscles. However, the child with cerebral palsy does not have this balance.

Another type of deaf-blind child is the one with retrolental fibroplasia (RLF). This child often has perceptual motor difficulties.

All deaf-blind children, regardless of etiology and additional handicaps such as hypotonia, cere-
bral palsy, or perceptual dysfunction, have problems with motor development. In assessing a child, especially in the early years, one of the most important things to use in screening is motor development steps or milestones (Gesell and Amatruda, 1947). If the child is not able to perform the steps in the prescribed sequence, he or she should be suspected of some kind of problem and should be referred to a physician or a therapist for diagnosis.

Motor Development Steps

The motor development steps can be used as a treatment guide as well as for assessment purposes. For example, if a child of any age is on one step, then the treatment goal would be to have him or her progress to the next step. When the child is examined, the whole child should be studied for the manner in which he or she moves his or her body. If the child moves very little, or he or she is irritable or cries for no reason and cannot be comforted, one should suspect some kind of problem. One should also be aware of the child who does not like to be touched. Many visually and auditorily impaired children are tactilely defensive; that is, they avoid or are startled by touch. The child should be observed in a variety of positions, particularly when he or she is on his or her back or stomach, or is sitting, or is being held upright.

The first developmental sequence involves rolling and crawling. In this sequence supine means on the back and prone means on the stomach. The prone position, on the forearms, is an important position to examine. A normal child will usually get up on his or her forearms to look around; however, the blind child will very seldom perform this act on schedule. Zones are the number of inches the child raises his or her head up off the mat. Rolling is also a very important step. Crawling and creeping are delayed in deaf-blind children. Usually, but not always, a child will progress from a crawl (with the stomach on the mat) to a creep (up on all fours). Any child who is not moving around the room in some way by forty weeks of age should be examined. A normal child is motivated to move about the room by objects or people he or she sees or hears. However, the deaf and blind child does not have this motivation.

The second sequence is sitting. The visually impaired child often has difficulty with holding his or her head erect and steady because there is no visual motivation for him or her to do so. Sitting erect momentarily and steadily is often delayed so that the child can learn the security of the supine position.

The deaf-blind child will have much difficulty with standing and walking. Researchers with the blind have found that these children will achieve static positions (still positions), such as sitting and standing, at about normal ages, but they have difficulty with the dynamic positions (movement) such as crawling and walking. I have found that deaf-blind children often have difficulty with both static and dynamic positions (standing and walking) because of tactile defensiveness, or they do not like to have their feet touching a surface. Some other important steps include the child pulling himself or herself to his or her feet at a rail (pulling up on an object such as a chair, table, or crib rail), or cruising at the rail (walking in a sideways fashion along a piece of furniture), or walking with one or two hands held (walking independently).

One should be suspicious of the child who cannot pull himself or herself to a standing position at one year of age and walk at fifteen months of age. Vision and hearing play an important part in why and how a child starts to walk. If a child is already walking, study how he or she gets around. If a child who has been walking for a while is extremely awkward or clumsy on his or her feet, one might suspect a problem. Many minimally involved hearing-impaired children are clumsy in walking because they are visually distractable. Many minimally involved vision-impaired children trip over low and small objects.

Fine motor control should also be assessed. One should study the way the child uses his or her arms and hands separately and together. At about three to four months of age the normal child will hold an object that is placed in his or her hand. The deaf-blind child very often will not do this because of his or her tactile defensiveness (they withdraw from touch because they cannot see the object). Eye-hand coordination, or the ability to see a toy and reach for it, begins at four to five months of age. However, this kind of motor action is not possible for the blind child. Eye-hand coordination, or the ability to hear a toy and reach for it, begins at about ten months of age. If a child does not develop this ability, of course, it would make one suspect deafness. In the development of grasping, the child progresses from the use of an awkward palmar (whole hand) to a precise finger-thumb grasp. A child who cannot grasp well by the age of twelve months should be suspected of motor control dysfunction.
Feeding, dressing, and toileting all are developmental milestones. These tasks, however, are much more likely to be affected by cultural differences such as when the child was weaned from the bottle or breast. A normal feeding development sequence usually starts with the child holding his or her bottle and then progresses to finger feeding, to using a cup, and to using a spoon.

I would also like to discuss briefly the De vec Developmental Screening Test, which was developed for people such as public health and pediatric nurses to screen children and for baby clinics and other facilities with all types of problems. The test is for ages ranging from one month to six years. It covers such areas as gross motor, fine motor-adaptive, language, and personal-social, and can be given with a minimum of time and equipment. The test is, however, a screening device only and is not meant to give a developmental age. It is used to alert the tester to the possibility of a problem so that the child can be referred for more specific testing.

Treatment Techniques

The subject of treatment techniques for the deaf-blind is too broad to try and cover in depth at this time. Therefore, I will discuss some general techniques that might be helpful in working with parents and schools.

Tactile Defensiveness

Tactile defensiveness starts early in the life of the deaf-blind child. A normal baby sees and hears his or her mother coming to pick him or her up, to feed him or her, or to bathe him or her. The deaf-blind child does not receive these clues and is often startled. This reaction triggers a vicious cycle that often ends with the child withdrawing from touch and is turned inward or appears to be sticky. As the child turns inward, he or she develops many of the self-stimulating and self-abusive behaviors often found with these children. Therefore, it is very important to interfere in this cycle as soon as possible. The parents and teachers should be helped in providing tactile clues so that the child knows what is happening; for example, touching the child to let him or her know that you are there, or gently pulling up on the child's arm to get him or her to stand. This action can be regarded as the beginning of communication with these children. When touching these children, one should be careful to touch firmly but gently, because too light of a touch is almost like a tickle and can be counterproductive. It is also important to know that, tactilely, the head and face are usually the most sensitive areas. If the child is defensive, rub his or her arms and hands with baby powder, lotion, different materials such as terry cloth and corduroy, or roll the child up in materials and make a game out of unraveling him or her. Play in different textures such as clay, sand, grass, mud, and popcorn. Bring the world in contact with the child. These children usually do not voluntarily touch or hold something. Therefore, one should use his or her hands to guide them in touching, holding, and exploring objects. The hand-over-hand technique is basic in much of the deaf-blind education and therapy. When this technique is used, the parent or teacher should fade his or her assistance as soon as possible so that the child will do it for himself or herself. Fading is done by gradually lessening the grasp of the child's hand and working down to the wrist and then to the elbow. Many curriculum guides on tactile stimulation are available for teachers and parents. An important thing to remember is that the objects one introduces to be touched should be of as many different sizes, shapes, textures, and temperatures as possible.

Motor Abilities

Motor abilities is another area of treatment. In development of both fine and gross motor abilities, it is important to remember that the deaf-blind child does not have the ability to imitate what he or she sees others do. He or she needs to experience normal postures, to be propped in the sitting position, to be held upright, and to be held and tossed as a normal child would be. In many cases the child has to be put into positions or through motions. Stimuli are needed to motivate the child to move forward by crawling or walking. Many children have enough vision to see a flashlight and will crawl or walk to reach it. Other ideas for walking include (1) walking the child with a sheet around his or her waist and holding him or her from behind and gradually loosening control; (2) having the child push around toys such as a chair or a table which will give him or her extra stability; (3) walking the child in all positions side by side, in front, holding on to an adult's arm or leg, walking forward, backward, and sideward with his or her feet on those of an adult; and (4) having the child walk and hold onto an object such as a broom stick, ruler, and rope, and gradually lessening the stability of the object. Movement should be used in space techniques to increase ability to move freely without fear to toss in a blanket, roll in material, roll on a large ball or foam roll; use a
trampoline, rocking horse, and swing between two people; and put a towel around the child's waist and lift him or her into the air and swing. The foregoing are just a few ideas to get the child walking. Later in life the child will be encouraged in other skills such as climbing steps, jumping, running, and hopping.

Perceptual motor skill such as spatial relationships, or knowing where his or her body is in space, are necessary for the deaf-blind child. If the child has any usable vision, he or she should be helped to locate certain landmarks such as a desk or couch so that he or she will know where he or she is. The child can be encouraged to trail along a wall to find his or her way around a room.

Developing body image is also important. This includes such things as knowing how big his or her body is that it is too big to fit under a couch but small enough to fit under a dining table. Obstacle courses are good for developing body image. Another needed skill is to be able to identify body parts on one's self or another person. For instance, if I touch his or her nose, can he or she find and touch my nose? For the older, higher-level child, concepts such as right and left and up and down have to be taught.

Feeding

Feeding is often a problem with deaf-blind children. Part of this problem can be the result of tactile defensiveness. Feeding and speech are connected movements, and well-coordinated mouth movements such as those used to suck, chew, and swallow are the foundations of speech. The normal infant spends a great deal of time mouthing objects, while the deaf-blind infant seldom does this spontaneously. The deaf-blind child may need hand-over-hand guidance to do this and to hold his or her bottle. If the child has difficulty sucking, one technique that often helps is to dip a piece of porous material, such as cheese cloth, into honey or a sweet liquid and have him or her try to suck the liquid out of the material. In teaching the child to drink from a cup, he or she should be started with small amounts of liquid; the child may have to be helped to close his or her lips on the edge of the cup. For spoon feeding a good sitting position is very important. The child's trunk should be upright, with his or her hips flexed, head in the midline and slightly forward, and chin down. At the outset small amounts should be placed on the spoon. The child should be allowed time to swallow completely before taking another spoonful. If chewing is a problem for the child, it may be helpful to manipulate his or her jaw up and down to give him or her the idea of the motion. To do this one should use a jaw control position with the thumb and two forefingers.

When one teaches chewing, the texture of the food should be changed gradually from smooth to lumpy to semisolid to solid. The child who does not chew much may have tender gums. The child's gums can be desensitized a little by gently massaging them with a finger prior to feeding time. One easy and safe way to hold the mouth open for examination of dental formation or for brushing teeth is to use several tongue depressors that have been taped together. If the depressor is inserted on one side of the mouth, one can work on the other side of the mouth more easily.

The parent should be encouraged to include the child in the preparation of the food if at all possible. This procedure will give him or her many good experiences in touch and taste, as well as showing. This procedure will give him or her many good experiences in touch, taste, temperature, as well as showing him or her that food just doesn't materialize out of thin air.

Reference

Readership Survey

For the last several years the Southwestern Region Deaf-Blind Center has distributed to those who work with deaf-blind and multihandicapped children the proceedings of its study institutes and workshops. The center is now endeavoring to determine how the proceedings have been received in the field and to what extent they have been used by the recipients. Therefore, it would be greatly appreciated if you would complete the following questionnaire and return it to the Southwestern Region Deaf-Blind Center, California State Department of Education, 721 Capitol Mall, Sacramento, CA 95814.

1. What is your appraisal of the information presented in the proceedings?
   __________ Great value
   __________ Some value
   __________ Little value

2. Do you make your copies of the proceedings available to other members of your professional staff?
   __________ Yes
   __________ No

3. Do you have any suggestions in regard to ways in which the proceedings or any other publications distributed by the center might be improved? If your answer is "yes," please write your suggestions or criticisms here or on a separate sheet.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

4. Do you wish to continue to receive the proceedings? Your name will be removed from the mailing list if you answer "no" to this question.
   __________ Yes
   __________ No

Your name:_______________________________________________________________

Position:_______________________________________________________________

Address: _______________________________________________________________
   Street

   City   State   ZIP Code