The Future of the Deaf-Blind Child: Proceedings of Special Study Institutes and Workshops.

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

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Fifteen papers from special study institutes and workshops focus on understanding planning, providing residential and community services, and training for the deaf-blind. Included are the following titles and authors: "Definition of the Problem" (L. Smith); "Normalcy of the Abnormal--Body and Sense Thinking Development of the Organically Impaired" (H. Wachs); "Educational Rights of the Handicapped" (R. Martin); "Trust Planning" (R. Kercheval); "Packaging a Program" (H. Murphy); "Residential Services--Support, Not Supplant, the Natural Home" (E. Skarnulis); "Philosophy and Procedures of the State Hospitals" (K. Larsen); "The Care of a Deaf-Blind Resident" (A. Fox); "The Deaf-Blind Program at Porterville State Hospital" (J. Clinton); "The Experiences of Benhaven and Their Application to the Deaf-Blind" (A. Lettick); "Community Support Systems for Deaf-Blind Adults" (J. Wolpert); "The Treatment of Severely Disturbed Children with Sensory Handicaps" (M. Frostig); "The Thrill of Victory and the Agony of Defeat" (H. Haas); "Auditory Training for Deaf-Blind Children" (E. Soper); and "Vision Training Techniques for Deaf-Blind Students" (H. Wachs). (SBH)
The Future of the Deaf-Blind Child
Proceedings of Special Study Institutes and Workshops
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Preface

In our continuing search for ways to help the deaf-blind, we often reach beyond the area of the deaf-blind's own expertise in other disciplines. None of us who work with the deaf-blind should think that we have all the answers to the many questions concerning the education of the deaf-blind—or even that we are clearly aware of all their needs. The deaf-blind sometimes need more help than we alone can give them in their efforts to become self-sufficient members of society. We welcome the help from whatever source and from whatever disciplines that can contribute to attainment of the goal of self-sufficiency for our children.

Over the years, therefore, the Southwestern Region Deaf-Blind Center has sought in all disciplines individuals who possess the kind of thinking and skills that can lead to a better life for the deaf-blind. Many experts in fields other than the deaf-blind never considered that there is an enormous population of deaf-blind persons who can benefit from new ideas and perspectives. It is always encouraging, then, when these distinguished individuals accept our invitation to share their knowledge and experience with us.

Many of the papers published here are the work of such individuals. All of these papers were originally presented at one of three occasions: (1) Special Study Institute, "The Future of the Deaf-Blind Child in the Community," August 20–23, 1976; (2) Workshop in Behavior Management and Vision Training, December 10–12, 1976; and (3) Winter Special Study Institute, February 25–27, 1977. A look at the list of authors will show that most do not work in the area of the deaf-blind, but each has contributed to the education of deaf-blind children by his or her presentation. We hope that these papers will help you gain new perspectives on your work and that the new perspectives will enrich your programs and the lives of the deaf-blind children you serve.

DAVIS W. CAMPBELL
Deputy Superintendent for Programs

WILLIAM A. BLAHA
Project Director, Southwestern Region Deaf-Blind Center
I. UNDERSTANDING AND PLANNING FOR THE DEAF-BLIND

Definition of the Problem

Lonlon H. Smith, M.D.

Any child who does not seem to be able to settle into the academic routine could be considered to have "education dysfunction." Each child responds to the stress, structure, or distraction of the classroom in his or her unique style. Because some become hyperactive, are out of their seats, and get nothing on paper, the teacher may not be able to evaluate their academic progress. Some are shy, withdrawn, appearing frozen, physically and verbally. Some appear doped, lethargic, or "in another world." A few may appear sick or complain of headaches and stomachaches. One or two may be belligerent, answering a reasonable request from the teacher with hostile defiance. And there is always the class clown who needs to hide deficiencies or anxieties by joking and making faces.

This partial list of dysfunctional types is estimated to account for 10 to 20 percent of each class. The teacher must try to motivate these children with humor, rules, discipline, or behavior modification programs, or some other technique to get the most out of them and educate them without making them feel bored, cheated, mad, scared, or inferior. The educational process must be fun (for the teacher also).

Ideally, the teacher should mold the class into an enthusiastic, education-oriented, cohesive unit with a minimum of "losers." However, a "pecking order" is usually established within a few weeks no matter how democratic one attempts to make the class. The bright, quick winners become the teacher's pets, and the silent/sullen ones become more entrenched in their withdrawal behavior. It would be helpful if the teacher had children of the same age, intelligence, and learning skills in one class. If he or she is working with the dull or overgraded, the intellectually gifted become bored and restless. If the teacher races along with the intellectually superior, the slow ones are lost and become depressed or resentful. The answer would be a homogeneously slow or fast class or a better teacher-pupil ratio: something close to one to ten would be best.

But life is never ideal, and one must make do with what is available. Teachers who enjoy the challenges of a restless and diversified class can find a way to allow each pupil his or her share of success. The more rigid the teacher's expectations, the more disappointed he or she will become as the class progresses and the nonlearners begin to fall behind. The teacher will unwittingly allow a class hierarchy to develop, and the ones at the bottom will become more dissatisfied, withdrawn, disruptive, depressed, and resentful of the whole educational system. The teacher may, to save face, begin to label these recalcitrants as "bad," "emotional," "sick," "undisciplined," or some other pejorative that indicates a lack of understanding at best or a cold, restrictive personality at worst.

Students learn at different rates and in different ways, but all children have an innate desire to learn. Success breeds success: if a teacher has the key and can find the lock to a pupil's style, both are rewarded. Education is a sort of osmosis—a constant interaction between the dilute student and the concentrated teacher. It is an interlocking of emotional ambiance which traps the student, holds him or her still, and allows the teacher to pour in the academic messages. Eyes, ears, nose, mouth, skin, and muscles are all involved in learning because all have sense receptors that carry stimuli to the brain. The pleasure centers in the brain must be stimulated, or the cognitive messages will not be retained. Learning has to be fun.

All the educational gimmicks are of no avail if children feel inferior or discriminated against. The chief message they are supposed to get from parents, teachers, and peers is that they are decent, worthwhile persons—or at least that there is hope that they will attain such a status: "Everyone gets a good self-image; education is secondary" should be the motto of every classroom.

It is not the teacher's job to judge children who do not seem to fit into his or her conception of a responsive pupil. The task of the teacher is to identify the ones with educational dysfunction and
either try to discover the reason for the difficulty and correct it if possible or refer the child to the appropriate person or agency for remediation. On first recognizing a dysfunction, the teacher must report it to the parents in such a way that no blame is implied: "There is a problem: what can be done?". The result should be that parents and teacher and child are all on the same side in a mutually supportive system viewing the difficulty as unemotionally as possible. If sides are drawn, winners and losers are created: the dysfunctional problem - not the child - should be the loser.

If a child is saying, "What? what?" and pus is coming from his or her ears, it would be logical to assume he or she has a hearing problem. If a teacher calls this "bad," then the badness soon becomes the reason for hyperactivity, and a once remedial trait becomes a fixed syndrome. The child, now labelled bad, does bad things. A self-fulfilling prophecy is launched.

A child will become hyperactive if unable to "hear or see well; if anemic (not enough oxygen being carried to the cognitive areas of the brain to allow learning); if suffering from lead poisoning (brain cells poisoned); if possessing a low blood sugar level (the metabolism of the brain cannot handle the incoming information); if lacking a vitamin or mineral (the brain needs vitamin C, vitamin B complex, calcium, magnesium, and others on a continuing basis to function); if allergic to some food; if bombarded by abnormal brain waves (cortex or cognitive areas are overwhelmed with interruptive electrical impulses); if preoccupied with domestic problems that use up valuable energy; if possessed of a perceptual handicap (for example, reverses E into 3, was is saw, cannot transfer the sound "cat" into the visual symbol cat); if ahead of the class or behind it (class has average IQ of 100, and he or she is functioning at 120, or vice versa).

He or she may have all or one or some of these problems. They are not mutually exclusive. Any of them may also cause a child to appear withdrawn hypoactive, the opposite of hyperactive. However, a student may be suffering from one or a few of the problems and still learn. If a student is not learning, it may be simply because he or she hates the teacher.

The common problem is educational dysfunction, when a child is not learning easily or at all. Nonlearning is easy to spot at the first classroom test: the pupil simply does not put anything down on paper. If this failure is caused by an inability to perceive the information, store it, retrieve it, or transfer it to a motor skill (recitation or writing), it is a dysfunction. The pupil may be hyperactive because of these perceptuomotor problems, or the hyperactivity may cause the perceptuomotor problems. Hyperactivity may be the cause or the effect; it is merely a clue that educational dysfunction is nearby.

One way to look at some of these pupils is to consider that they are suffering from a sensory input overload; the cortex of the brain simply cannot handle or process all the messages. A defective filtering system in the brain seems to be the common problem. All incoming stimuli must pass through the filtering area of the midbrain before they are sent on to the cortex, or cognitive area of the brain, where perception occurs. If the screening mechanism is incompetent, too many messages go through to the cortex and the brain feels it cannot cope and perceives the world as a threat.

This overabundance of incoming stimuli is manifested as stress and can lead to one or more of several responses, depending on a variety of factors: previous experiences; age; diet; genetic predispositions; brain damage; abnormal brain waves; heavy metal poisoning; amount of sleep the night before; state of the bowels; drug ingestion; presence of anemia, infection, or allergy; vitamin intake; blood sugar level; interest in the environment; boredom; the state of the self-image; or tight underwear.

In general, three types of responses may be expected when the child's cortex perceives incoming stimuli as stress: (1) the brain might send messages to the autonomic nervous system, which produces the somatic manifestations of anxiety (rapid heart beat, panic, fright, stomachache, headache, sweaty palms); (2) the cortex might send messages to the motor area of the brain, where action, movement, and speech are initiated; or (3) the brain might stimulate some inhibitory area of the midbrain, causing withdrawal (avoidance of eye contact, removal of self from activity: noncompliance, hypoactivity).

If the filtering system is feeble or inactive, too many stimuli get up to the cortex. If the cortex is compromised (possibly due to birth injury, toxins,
show that even minimal stimuli can cause a similar overload. Children afflicted with hypoglycemia are unable to disregard important stimuli. They are ticklish children and grow up to be sensitive adults. They are more likely to be colicky, wakeful, and allergic. They believe a minor stomachache is an appendicitis attack. They will touch every picket when walking by a fence. They will see a dog and pet it; see a button, push it; see a candy bar, take it. If the phone and the door bell ring simultaneously, they are unable to set up a priority system; their response is to fall on the floor.

Many children have another problem, acting singly or in combination with the ineffective filtering system and the overly responsive cortex: hypoglycemia. Reactive hypoglycemia can produce all the symptoms of hyperactivity. A carbohydrate breakfast consumed by susceptible children has the potential of forcing the pancreas to excrete too much insulin. An overabundance of insulin drives the blood sugar down too fast and too far. The body reacts to this chemical stress by secreting cortisol and adrenalin, which are the body's main chemical response to stress. These chemicals suggest to the body that fright, flight, or fight would be appropriate responses. Every class has at least one child who shows the resulting signs of restlessness and aggressiveness.

All child care specialists agree that something must be done to help these children, not so much because of their academic failure as because of the devastating effect on their self-image. If parents, peers, and teachers are all saying, 'You could do better,' 'Hey, stupid,' 'What a jerk,' 'Look at that,' or 'Share up,' a child will become depressed, angry, and resentful. It may be one step to the mental hospital.
Part one of this article was written by H. G. Furth as the theoretical basis for a forthcoming preschool evaluation instrument—The Wachs Analysis of Cognitive Structures.* It is included here as an excellent discussion of Piaget’s theory as applied to body and sense thinking. Part two presents some views on body and sense thinking of the organically impaired and the universality of human cognitive development.

The two parts present the view that human thinking development is species-specific and does not vary because of impairment, but rather follows the same stage development. Therefore, the sequence of presentation of intervention tasks is the same for all children—impaired or nonimpaired. The impairment dictates the method of presentation, not the developmental approach.

Piaget’s Theory and Sensorimotor Functioning

Piaget’s theory of intelligence is popularly known as a theory of “stages,” which follow each other in lawful succession from the initial sensorimotor period of the prelingual infant via the preoperatory period of the preschool child to the periods of concrete operations and formal operations beginning around ages six to seven and eleven through thirteen, respectively. Along with this view it is often erroneously believed that a child in interaction with the environment moves through these stages somewhat as a child advances in years toward adulthood, except that the rates of stage-to-stage transition vary among individuals just as intelligence varies in the population. Of course, reaching a stage sooner is supposed to be more favorable for the final intellectual functioning of a person, hence the misguided impulse to train children in stage-specific tasks in the hope of advancing their intellectual abilities. Moreover, since intelligence is known to be a general ability, not linked to specific subject matter, the false impression is created that these stages more or less uniformly cover all important intellectual activities; and once a stage has been passed, a person under normal circumstances would not revert to a former low-level functioning. It would follow that after around age two a child has moved beyond the stage of sensorimotor functioning, and scholars and professionals concerned with the child’s intellectual development should look toward the operational functioning of subsequent stages. Piaget’s own work appears to confirm this view. He proposes six substages during the sensorimotor period, after which there is hardly any mention of sensorimotor functioning, as if it disappears altogether or were entirely absorbed by the following stages.

This misreading of Piaget’s theory can be rectified by reference to a few facts. First, Piaget’s interest is narrowly focused on theoretical logical-mathematical concepts that form the basis of modern empirical science, concepts such as classification, quantity, and deductive reasoning. His stages have their full meaning only with respect to these. Second, Piaget searched for the source of these logical-mathematical concepts in the biological functioning of the person, rather than in social-verbal transmission or some innate program that needed only time to mature. For that purpose he studied a child’s activities back to the very beginning of the child’s life, namely, the pretheoretical period, which he called the sensorimotor period. Third, Piaget observed the basic adaptation of an infant to the environment in terms of such observables as sense and motor coordination, intentionality, means-end relations, physical causality, and object permanence. He thus described six substages of sensorimotor functioning. But in no way did Piaget study specific areas of sensorimotor functioning. Furthermore, as soon as the child manifested the first glimmer of theoretical intelligence by grasping the concept of the permanent object—that is, differentiating between the objective existence of things in the world and the existence of self and subjective
activity—Piaget focused on the further development of theoretical functioning. Fourth, he never implied that sensorimotor functioning is achieved by age two. Piaget was satisfied to have demonstrated that the source of theoretical intelligence is the general coordination of the practical actions of sensorimotor functioning. Fifth, children do not come in stages; general logical concepts do. Thus, for instance, there is understanding of space or quantity at the sensorimotor stage, at the preoperatory stage, and at the concrete and formal operatory stages. But a person's everyday functioning is never limited to one stage, since it includes aspects of intellectual functioning that are far removed from potentially formal-logical concepts. Hence we should not say, "The child is in a stage" but always limit the stage description to a particular concept; for example, "This child understands liquid quantities at the stage of concrete operations."

What is the use of Piaget's theory for those interested in the child's intellectual development if stages do not extend across a wide variety of intellectual activities? Human activities would not be human if they were not informed and coordinated by intellectual rules. A unity of intellectual functioning encompasses all human activities just as there is a basic continuity between the most abstract theoretical reasoning and the most primitive sensorimotor coordination, such as hand-eye coordination. This idea of intellectual unity is one of the main tenets of Piaget's theory. But at the same time and in another perspective, there is discontinuity and simultaneous functioning at different levels: at no level is knowledge a unidimensional, absolute thing or simply a piece of information. Knowledge in Piaget's theory is always relative to an individual's available cognitive structures for assimilating, coordinating, and transforming incoming data, thus turning them into something that is known. The paradox of unity and discontinuity makes the theory hard to understand, but also makes it appealing and relevant to the dialectic process of knowing, a process that structures both the subject and object and regulates the interaction between subject and object. This process of knowing, in its regulatory aspect, is common to all living phenomena; yet, in human development it takes on qualitatively different structural characteristics, which Piaget calls stages.

This development is most readily seen in the narrow area of logical-mathematical knowing, on which Piaget focused and in which he postulated three or four different developmental stages. There are, however, many other acquired capacities in which one can observe clear developmental progression without being able to find clearly defined stages. The crucial factor, therefore, is not the stage concept as such, but the developmental perspective. What precisely is meant by the word developmental? It is to be distinguished on the one hand from "learning from without" and on the other hand from "maturation from within"; in fact, it could be said to be "learning from within."

These distinctions can be easily explained in sensorimotor functioning. For example, learning to walk requires the physiological maturation of neural connections and the weight distribution of body parts. Then specific social and spatial constraints must be learned "from without." The infant becomes familiar with the environment in which he or she walks. But finally, the acquisition of the ability to walk purposefully in any environment is a developmental learning from within, a "know-how" that coordinates body balance and general movement processes with spatial coordination as mediated by touch and vision. Acquiring the ability to walk is not merely internal maturation since it requires the experience of living and moving about in space; but neither is it primarily the result of facts or information initiated from outside, something that must be remembered; something that could be forgotten. It is a developmentally acquired structure of behaving, a practical know-how, an action-knowledge that a person acquires by an active construction and not simply by learning from without by means of language or imitation. For example, understanding probability means assimilating the theoretical structure of probability and using the structure appropriately; it does not require that the probability structure be stated in verbal discourse. In the same way walking means assimilating visual-spatial and proprioceptive cues to the know-how of walking.

Sensorimotor functioning is thus a clear example of a developmental capacity. Developmental capacities certainly do not stop at age two, the point at which Piaget stops investigating their development. There are well-known sensorimotor activities which become coordinated at a much later age, such as sport activities, bicycling, drawing, and using tools accurately. The present inventory documents the variability of body and sense functions that do not reach stability until the child is well into the primary school age and at the same time there is the expected spread of individual differences within a given age group. The special functions of the Wachs Analysis of Cognitive Structures are in
the area of visual, manual, graphic, and movement coordinations. Other specific functions, such as auditory, rhythmic, and discriminatory coordinations—by means of vision, finger, lip, and tongue—are mentioned in the addendum to the book.

To postulate that these functions are developmental acquisitions is to claim that they are the products of an inner-learning or construction and that in this respect they share the properties of all developmental acquisitions. "Body and sense knowledge" is human intelligence applied to the understanding of the body's functioning, just as theoretical knowledge is the application of intelligence to theoretical problems. Developmental knowledge, as stated before, is a general know-how or understanding, not a static quality taken in from the environment, imitated or touched in verbal language, and subsequently remembered. Theoretical knowledge derives from the earlier stages of sensorimotor functioning: reciprocally, theoretical cognitive structures feed back into sensorimotor functioning. Additionally, a child with theoretical structures of operations or preoperations can reflect on sensorimotor functioning, becoming conscious of the underlying mechanism and representing it for himself or herself in symbolic communications to others.

Preschool years, before children acquire the first fully-developed concrete operations, are the most appropriate time for them to apply their intelligence to the challenging task of stabilizing sensorimotor functioning. In fact, for children of this age, the use of the body and senses intelligently is a high-level thinking task that gives them the experience of using their intelligence at an optimum level and getting to know themselves. It is meaningless to ask to which stage the intelligent coordination of body and sense belongs since Piaget's stage concept is concerned with theoretical functioning while body and sense coordination is primarily practical functioning. It is enough to recognize that developmental processes are involved and that references to different levels of sensorimotor functioning reflect an empirically observable increase in the complexity of body and sense coordination without the claim that these levels correspond to qualitatively different structures as Piaget claims for his three main stages (the sensorimotor, the operatory, and the concrete and formal).

In conclusion, Piaget's theory contributes to an understanding of sensorimotor functioning by giving substance to the idea of knowledge as a developmental process. Sensorimotor functioning is vital in its own right, and the emphasis placed on the intelligent use of one's body and senses hardly needs to be justified. If that use is not innate, not merely the outcome of an automatic maturational process, then it is an example of developmental learning in Piaget's concept of development. Moreover, the more advanced acquisitions of sensorimotor functions are probably greatly influenced by the developing theoretical structures without ceasing to be primarily sensorimotor functions.

However, if one's interest were merely in theoretical knowledge, even then an understanding of sensorimotor function is almost obligatory. It is clear that better developed sensorimotor schemes can be more readily used in the service of theoretical schemes. Theoretical tasks do not exist in a vacuum. Ordinarily they make a large number of visual demands and are stressful in terms of body balance. To sit quietly and focus one's eyes on a book held at close range is a biologically and psychologically constraining situation. If the body is preoccupied in coping with the stress created by these external demands, the theoretical schemes are not likely to function smoothly and efficiently.

Finally, there are some aspects of theoretical knowledge that are even more directly linked to sensorimotor functioning than the general relations discussed in the two preceding paragraphs. Many aspects of reading are direct applications of sensorimotor functions, as are aspects of geometry and the understanding of spatial coordinates. Understanding the concept of "same and different" and of one-to-one correspondence are also directly derived from sensorimotor functions. In the balanced person, who has well-developed lateral cortical functions and integrates them appropriately, the integration of functions is again not an automatic maturational process. It is a true developmental process which can be fostered or hindered by the use of sensorimotor functions even though in turn the cortical integration will influence— for good or ill—both the sensorimotor and the theoretical functioning of a person.

II

Body and Sense Thinking and the Organically Impaired

Sensorimotor, or as I prefer, "body and sense," thinking can be divided into six aspects:

1. General movement: aggregate body movements for locomotion or body position
2. Discriminative movement: isolated movement of specific parts for specific action, namely,
movement-deprived kittens that proved to be less adequate in a visual locomotion demand task demonstrate the importance of assimilation of movement and visual thinking. Recent split-brain studies have shown that information from the sense organs is dependent upon specific hemispheric function for cognition. Retrieval studies of split-brain individuals showed success in left-hand identification of objects but failure in labeling them. Right-hand identification by the same individuals was successful in label as well as retrieval. Similarly, the left visual field (right brain) showed better recognition of designs than the right visual field (left brain); and the left hand (right brain) showed better graphic reproduction of geometric figures than the right hand (left brain). These studies indicate that much more is involved in knowing an object than the organ of neural input. Furthermore, these studies are neurological and physiological support for Piaget’s theory that cognition is pervasive of the total human organism and is not solely reliant upon specific sense organ input.

Mental image varies among individuals as well as within the same individual, depending on the body or sense aspect involved. In a work-study program at Tel Aviv, Israel, a thirteen-year-old girl who could not graphically reproduce a simple linear design summarized the effects of such cognitive confusion in humans by stating, “I know what you want, but my hands won’t draw what my eyes see!” Thus it is that one sense modality, such as vision, can support or confuse other body-sense mental images dependent on the absence or existence of appropriate cognition schemes.

Teachers and therapists of the organically impaired must keep in mind this varying mental image and particularly must avoid projecting their own response as the duplicate of the organically impaired individual’s. Since cognitive development occurs only through high operational thinking and since such thinking can be evaluated only by some overt response from the student, the teacher must monitor two equally important diagnostic factors of the student’s response: (1) listening to what the child says; and (2) observing the child’s actions. The teacher must constantly determine how to alter the complexity of the environment to perpetuate the student’s high-level thinking yet avoid too high a demand and discourage or frustrate the student.

Present American society places too much emphasis on academic attainment as the major educational goal, often to the exclusion of cognitive-social development. Is not the attainment of success as a member of the human society...
more appropriate goal? Clinical experience has shown that development of body and sense thinking is a function of all humans; academic success is cultural. An intellectually healthy child usually has no difficulty with academic skill acquisition, but the acquisition of good grades in school does not necessarily promote intellectual health. An individual denied cortical access by one or more organic impairments must conceptualize through an alternate mental image. The realistic application of this compensatory mental image is directly dependent on the individual's available cognitive schemes. Thus, early development of available body and sense thinking of impaired individuals is especially important to promote their stage development toward more formalized logical reasoning in order to avoid their becoming mechanical "doers" and to encourage their development toward becoming eventual "formal thinkers".

References


Educational Rights of the Handicapped

Reed Martin
Director, Project on Law and Behavior, Houston

Professionals in programs for the handicapped are being challenged by three recent federal laws as they have never been challenged before. Children who have been excluded from special programs must now be served. And all individuals who were once served must be addressed in individual program plans for which staff is held strictly accountable.

In 1975 the Congress enacted the Education for All Handicapped Children Act, which is addressed to virtually all types of handicap. Congress also enacted the Developmentally Disabled Assistance and Bill of Rights Act, which includes provisions for the mentally retarded, autistic, cerebral palsied, and epileptic. Many children will be covered under both laws.

Two years earlier Congress passed the Rehabilitation Act, which included in its provisions a prohibition against discrimination on the basis of handicap. It is broader than the first two laws mentioned. The Rehabilitation Act is the law of the land now, while the Education for All Handicapped Children Act and the Developmentally Disabled Assistance and Bill of Rights Act are just now being implemented.

Together these laws provide substantial rights for the handicapped. First, they establish eligibility criteria which apply to virtually any handicapped person. Thus, all must be served in a free public program appropriate to individual needs.

Second, procedural safeguards of notice and consent are strengthened. Notice must be given prior to each step in providing services: identification of an individual suspected of having an eligible handicap, evaluation of his or her specific needs, placement in a program, evaluation of progress, and so forth. In most cases, consent is required after notice. A pending Supreme Court case may influence whether consent must be obtained from the child as well as the parent. Service providers should be attentive to problems relating to parents' being coerced into consent or not truly being informed about the subject matter of the consent.

Third, if the parents, or the handicapped child, refuse to consent or if they decide at any point to challenge a program, they have the right to a hearing. They have the right to see all records relevant to the client. They may be accompanied by an attorney and an independent expert. They may present evidence at the hearing and cross-examine service providers. The whole hearing must take place before an independent hearing officer, and the parent has the right to appeal.

Fourth, if an individual is identified as eligible, services must be offered. Lack of funds is no excuse for not providing services. Children cannot be excluded; once included, they would be very hard to remove under the subterfuge of suspension or expulsion.

Fifth, the determination that an individual is eligible must begin with a fair assessment. That assessment is very important because it forms the basis for the individual plan under which services will be offered. All possible problems must be assessed; and the method of assessment must not reflect cultural or racial discrimination. Service providers must notify clients, who then have the right to obtain an independent assessment. If an educational program is at issue and the independent assessment is more appropriate than the school's assessment, the school must reimburse the parents for the individual assessment.

Sixth, when considering placing a client in a program, the service provider must consider the Fourteenth Amendment's requirement that each person be afforded the equal protection of the law. If a school has predominantly white children assessed as "learning disabled" and mostly black children labeled "educable mentally retarded," the school has a problem. If the facilities, staff, and resources for the programs for the handicapped are not comparable to those offered to nonhandicapped clients, that, too, is a problem.

Seventh, when served, the client must have an individual program plan. The plan must be developed at a joint conference which includes representatives of the service provider, the parents, and
the handicapped client. The writers of the plan must assess current levels of functioning and convert that assessment into a statement of goals. The goals must be stated in terms of what can be accomplished by the end of the year and in terms of measurable intermediate steps leading to each annual goal. The services that must be provided for each step must be listed, with the date for beginning, the anticipated duration, and the name of the individual providing the service along with his or her qualifications. An evaluation plan, criteria to measure progress, and a schedule for periodic review must also be provided.

Eighth, services must be provided in the least restrictive feasible setting. That means alternatives must exist, and they must be considered realistically. When any less restrictive alternative is rejected, a statement of the reason for rejection must be made.

Ninth, the law recognizes that handicapped citizens have been subjected to many abuses, and new federal requirements offer a general protection against harm. One kind of harm comes from long-term isolation into a narrow treatment program. Thus, clients must be in normal settings during as much of the day as possible and in special programs for only short periods.

Another kind of harm comes from potentially hazardous approaches that get out of control. The law requires that procedures be regulated in writing and be under the control of staff members who have demonstrated their competence at an acceptable level.

Harm can also result from overuse of medication. Federal law prohibits the use of medication as punishment, as an aid to custodial care, and as a substitute for a real program of aid or when it hampers other programs. Even if medication does not violate one of those prohibitions, it may cause long-term irreparable damage.

Harm may also result from requiring the handicapped to work or from placing them in spurious work assignments in which they provide labor to the institution but receive no wages. Handicapped clients must also be protected from "unreasonable" corporal punishment. The Fourteenth Amendment, as interpreted by the Supreme Court, requires extensive due process before any normal child can be subjected to corporal punishment. It is highly questionable whether a child with physical or mental disability could be subjected to corporal punishment.

Harm can be caused by placement in a facility in which conditions are below the minimum standards that are required in a long line of federal cases. Public schools that place children in other facilities for treatment of a handicap bear the responsibility for any violations in that facility, whether it is public or private.

Tenth, the law provides for certain administrative responsibilities in addition to those required to enforce clients' rights directly. The main responsibility involves recordkeeping. Parents and clients must have access to records and be informed of their right to a hearing to contest information in the records. Records on which treatment decisions are based must be adequate, and decisions must be made on the basis of the records. All information must be treated as confidential, with access only in accordance with federal law. Unnecessary use of information in a way that stigmatizes the client must be avoided.

Eleventh, staff training is mandated for anyone who has contact with the handicapped. Personnel must be trained to deal with the client's specific problem, with other professional personnel, and with parents and others who must be involved in the planning and treatment process. Staff must also be supervised so that when mistakes occur, they can be discovered and remedied as soon as possible.

A growing number of persons—compliance officers, client advocates, and attorneys—will try to see that the letter of the law is obeyed. However, full services and full opportunity for the handicapped will be offered only if service providers respond to the spirit of the law as well.
Trust Planning

R. M. Kercheval
Trust Department, Bank of America

After the planning of an estate, the next phase is the carrying out of the plan. In this article the emphasis will be on providing for deaf-blind beneficiaries, including what can be expected of the various arrangements and how these arrangements are implemented. Financial provisions for deaf-blind persons fall into two general categories: (1) the direct provision of support by the family or other individuals; and (2) the contribution of funds to organizations which can provide this support.

The first alternative—support by the family or other concerned individuals—is the most obvious one. Even in such cases some sort of contingency arrangement may be needed in the event of the death of the mother or father, uncle or aunt, or the kind person who is providing support. Also there may be certain other advantages to an arrangement other than direct support. One method of providing support is by making gifts to deaf-blind persons. There are possibly estate and inheritance tax advantages to this form of arrangement. However, a direct gift of money or income-producing property might require a trust or a guardianship if the deaf-blind person is not able to manage it himself or herself. A guardianship would have to be supervised by the court. As an alternative a bank or an individual could be appointed to act as trustee under a living trust agreement, thus providing the support directly through a living trust.

The living trust means that the person establishing it is alive. It is a very flexible arrangement that can be made to cover all situations. A living trust can be made revocable so that it can be terminated or amended as the circumstances or the desires of the person establishing the trust change. It can also be made irrevocable, in which case it cannot be changed. The irrevocable trust offers certain income tax and estate tax advantages. But it also has an obvious disadvantage: once it is established, it can never be changed.

Another form of trust includes the best of both the revocable and the irrevocable trusts. It is called a Clifford type of trust. A Clifford trust is irrevocable for at least ten years, at which time it can revert to the person who established the trust. This arrangement shifts the income tax responsibility from the person who owns the property to the beneficiary, who is usually in a lower income tax bracket. The person establishing a Clifford trust would have to have some property that he or she is willing to give up the income from for at least ten years, an arrangement that would appeal, of course, only to somebody in a fairly high tax bracket. For instance, a person may receive $1,000 a month from the property, but have to pay $500 of it in taxes because of his or her tax bracket. To give $500 for the benefit of a deaf-blind person, such a person would have to earn $1,000. But under the provisions of a Clifford trust, the $1,000 could go to the deaf-blind person without being taxed, and the one establishing the trust would be in a lower tax bracket—a very desirable type of trust under certain circumstances.

Another type of arrangement is the testamentary trust, one that is established in a will and does not come into effect until the person who made the will passes away. Within such a trust a direct bequest could be made to a deaf-blind person. If the beneficiary were not able to care for himself or herself, a trust or a guardianship would have to be established. Like a living trust, a testamentary trust could provide a complete arrangement, taking care of all the financial details for the deaf-blind person. Basically, then, there are two choices: the living trust and the testamentary trust.

The administration of these trusts is the business that my bank and I are in. The purpose of these trusts, of course, is to protect the interests of the beneficiary while providing support. There are cases in which unscrupulous operators have taken advantage of gullible people, people who have come into money but have never had business experience. Some "blue sky" operators will talk them into an investment, and the first thing they know they have lost their money. There are also cases in which well-meaning advisers, who may be
very close friends, cause the dissipation of a substantial estate. Such losses often happen because the well-meaning friends see investments differently from the way a handicapped person would. They may be able to risk a certain amount in order to appreciate their capital. And if they lose their money, they can earn it back again. But a handicapped individual only has so much, and if it is lost, it is gone. Investments cannot be static. They have to be watched continuously. A good investment today may not be a good investment tomorrow or next year. Things change. Careful investing requires continuing surveillance.

This is where the trustee comes in. A trustee can provide professional management of the assets. Generally, a bank trustee operates under what is called the prudent person policy. This means that the trustee will invest the assets that are in his or her trust for the benefit of the beneficiary, as a prudent person would invest his or her own property. Generally, such a policy is conservative. However, the policy and the practice must gear the investment to the requirements of the beneficiary. One beneficiary might need all the income that can be generated from a trust. Another might not need all the income. In the latter case part of the money could be invested in an appreciation type of investment to help counteract the effects of inflation through the years. Again, any such decision must meet the requirements of the particular beneficiary. Even the beneficiary's requirements can change, being greater or lesser now than they were ten years ago; therefore, the investor has to be flexible.

Personnel who work in the corporate trustee field are very well qualified professionals. They are well trained in the many facets of this business: investment analysis, portfolio management, tax planning, and day-to-day administration. No one person does all this, but a whole team within the trust department works together to get the most it can for the beneficiary.

With a corporate trustee there is no possibility for the assets to go astray because the assets are all kept separate from all other financial organizations' assets. A bank, of course, is highly bonded; therefore, if it were to fail, the assets would still be there. There is no risk in that regard. It is possible that the value of the trust investments will decline before it rises, but the assets will be safe. Nobody will go to some foreign port with them.

The mechanics of the administration of the trust are of great interest, of course, and particularly in the case of a deaf-blind beneficiary. The document under which the trust is established is what governs. The document could be a trust agreement, as in the case of a living trust, or a will, as in the case of a testamentary trust. The document controls many of the trustee's actions as well as his or her discretion. An attorney's assistance is most important, because the trust must be written so that it will carry out the benefactor's plan. Many decisions can be left to the trustee's discretion or none at all or a limited number. This control is very important.

The administrator is a person who actually manages the trust for the beneficiary. He or she is the point of contact, the person in the trust department, whom the beneficiary can communicate with. The administrator knows all about the trust. He or she should have a great personal interest in the beneficiary and try to keep informed of the beneficiary's requirements.

The trust instrument, a document or a guide that gives certain discretions to the trustee, can be a fairly broad one that quite commonly gives the trustee the power to use an estate's income or its principal for the health, welfare, support, and education of the beneficiary. This very broad discretion has to be implemented by an intelligent and reasonable person. In a bank, that discretion is usually exercised by the "trust committee." The administrator does not have absolute command of the trust. The trust committee is a group of experienced senior people in the bank, not all from the trust department.

The head of the trust department is on the committee along with other qualified senior heads of other branches, who have had a great deal of experience with people, with real estate, and with investments. The committee discusses questions and makes decisions in light of the trust document's instructions. Generally, if the trust agreement is written properly, the committee will be able to provide anything that is required by the health, maintenance, support, and education clause.

Committee members usually base their decisions on the beneficiary's standard of living. For instance, if a person who drives a Chevrolet requests a Ferrari, chances are that person will not get it; he or she will get a Chevrolet. A very important aspect of the operation of the trust is the understanding, intelligent, and conscientious group that makes the decisions that the father and mother would make if they could. In the case of a testamentary trust, court approval is also required in many discretionary decisions. Judges very infre-
I recently disagree with the trust committee, but it is possible that they might.

Besides providing direct support for deaf-blind persons, a benefactor can contribute to organizations which can perform this function. Many handicapped persons are not fortunate enough to receive direct assistance from their family, friends, or other benefactors. They have to look to other sources. There are organizations which can provide financial help. Private organizations will be dealt with here—as opposed to governmental organizations, which are established under law and have their own regulations. There are existing organizations with chapters that would help deaf-blind persons. Organizations could also be formed specifically for this purpose. Tax laws encourage support of this form of organization; therefore, people with substantial assets are inclined to be charitable. They receive tax advantages, both state and federal, by so doing. Support of these organizations can include contributions from individuals or, conceivably, grants from other organizations. An organization geared to assisting the deaf-blind might receive a grant from the Rockefeller Foundation or a similar organization. There is more than one source for this type of money.

Many communities have charitable foundations called community foundations. The trustees or directors, who are leaders of the community, periodically have fund drives, requesting donations from members of the community. Thus, they build a fund that can be used for many charitable purposes. The directors, of course, determine what the money will be used for.

Some financial institutions, such as banks, can also provide such a public service. This option is more popular in communities that do not have a community fund. The Bank of America has such an organization, called the America Foundation. It is a charitable, nonprofit organization operated by the bank to accept contributions. The contributions can be made for the general benefit (in which case the directors decide the beneficiary) or for a specific purpose. For instance, somebody could contribute a certain amount to be used strictly for deaf-blind individuals. The advantage of this form of operation is that it makes use of a well-organized trust operation at a minimum charge. It would cost too much, for instance, to manage a trust for $10,000 to $20,000 as an individual trust. But in the case of such organizations as the America Foundation, there is minimal expense. The bank provides the service as part of its community effort.

Private foundations are another source of funds. Private foundations, usually established by wealthy philanthropists, are often extremely large. Through private foundations wealthy persons can set up an organization geared to a particular charitable purpose. The Rockefeller Foundation is one of the best known, but there are many others.

There are two general forms of contributions that can be made to these different forms of organizations. One is an outright gift. This type is exempt from state and federal income taxes, but there is no possibility of using the money any more or getting benefits from it. Therefore, there is the second form, called “deferred giving.” In this form of giving, three arrangements are allowed by law: a unitrust, an annuity trust, or a pooled income fund trust. In a deferred giving arrangement, somebody can receive the income for life, and maybe his or her spouse can receive it afterward. After the death of both spouses the remainder—and whatever else has accrued goes to the organization. The Pomona College Organization was one of the early proponents of this type of arrangement. The organization does not receive anything right away, but the fund builds to a sizable balance as it matures.

Professional services are available, then, to assist deaf-blind persons by the use of trusts. In case of a family or individual, they can either be set up during the provider’s life or after his or her death. Proper planning can result in tax benefits as well as management and protection of the beneficiary. Tax-exempt organizations can also be used as a source of benefits for the support and education of deaf-blind persons. Existing organizations can be used if they are suitable. New organizations could be formed for this specific purpose. Either would be operated under some form of trust grant.

The biggest mistake people make is to overplan. It is like “overkill” in estate planning. Some people say, “I made this will for you; and no matter what happens in the next 30 years, or if you live to be a hundred, it will take care of everything.” That is gross overplanning. A will should be based on present circumstances and foreseeable circumstances. And the foreseeable is usually within four or five years.
Wrapping a package is frequently a family affair. Someone assembles the needed thing, someone wraps, someone applies the Scotch tape, and someone holds the ribbon while the bow is being tied. This is how it works in program development, too. The process begins with a need, or a list of needs. Persons responsible for developing a proposal should write that they consider to be the greatest unmet needs of deaf-blind children and adults. They should be very selfish, including the unmet needs of their children or of their parents, or the unmet needs at their place of work if they work with deaf-blind youth and adults. The proposal can be very specific, or it can be very general, perhaps attempting to set down the unmet needs in the field at large. It does not matter whether there are 5 or 50 needs. The needs should be tabulated and arranged by priorities in some way, emphasizing the greater needs over the lesser.

The next step is to look for a funding agency with the same priorities. The first logical stop is the regional deaf-blind center. The more support there is for an idea (such as a broad-based needs assessment), the stronger the proposal. Chances are the center would be interested in funding a good project if it met the following basic criteria: (1) an alignment of the project's priority with priorities imposed on the center by legislation and federal policies of the Bureau of Education for the Handicapped; (2) availability of funds; (3) quality and quantity of competing proposals; and (4) equitable distribution of funds throughout the region.

Work on the proposal may start with an outline or a written narrative emphasizing and justifying the need. The proposal should be completed in accordance with the federal proposal format, which usually includes a precise statement of objectives and methods, an evaluation plan, and a detailed budget. The center may encourage the writer of the proposal—not as an individual, but as a part of an organization serving deaf-blind individuals—to submit the proposal to the center itself. There it undergoes a rigorous and objective review by panels composed of parents, teachers, administrators, and others involved in the field. Proposals are checked to see if they are complete, if the need is indeed great and appropriate, if they fall within the legislative mandate of the center, and if the rest of the package is consistent. After the reviews the panels decide (1) to fund as written; (2) to fund after some modification or negotiation; or (3) not to fund.

The center may have to refer applicants elsewhere. Certainly, it cannot meet the needs of all its clients. However, a host of federal agencies also fund programs for the handicapped. Within the Bureau of Education for the Handicapped, which administers the centers for deaf-blind children, are agencies for handling special research and demonstration projects, experimental preschool and early childhood programs for handicapped children, media, physical education, and teacher preparation. The areas overlap, to be sure; but choosing the one or two agencies with specific responsibilities for meeting the identified needs will save time.


At California State University, Northridge, the Southwestern Region Deaf-Blind Center funds a program called The National Leadership Training Program.
Program in the Area of the Deaf-Blind. The purpose of the program is to train leaders to identify needs, to package and implement funded projects, and to administer programs of all kinds. Because of the great needs in the field, two proposals that were first developed as class exercises by graduate students were funded. Each of these, one in Colorado and one in Kentucky, was granted about $70,000 in the first year. Several students from the program have interned in the deaf-blind centers across the country. Several are having written projects published and distributed by the centers. The impact of this training program is great, and results tend to happen reasonably quickly after training. We who work in the program are proud of that.
II: PROVIDING RESIDENTIAL AND COMMUNITY SERVICES FOR THE DEAF-BLIND

Residential Services: Support, Not Supplant, the Natural Home

Ed Skarnulis, ACSW
University of Nebraska Medical Center

This paper will trace the history of services for the mentally retarded from the beginning of such services to the present and will illustrate some trends that can be deduced from that history. After spending nearly a third of my life working with handicapped persons, I discovered that one of those trends has been a growing aura of mysticism which surrounds what professionals do for handicapped people and their families. Obviously, handicapped citizens deserve more than gobbledygook and hocus-pocus explanations of what is wrong and what can be done to help. Operating on the assumption that some principles involved in treating the mentally retarded apply equally to citizens who have other handicaps, I was eager to share my experiences. My special interest has been in developing “less restrictive alternatives” in residential services for people who are severely or profoundly mentally retarded and physically handicapped as well. The number of these children and adults who are deaf and blind is small; therefore, I lack specific expertise in working with the deaf-blind.

History of Services for Mentally Retarded Citizens

Just as all persons who work with the deaf-blind can identify an important individual like Helen Keller as their inspiration, in mental retardation there are milestones which, although unrelated to one individual, mark a new awareness that far more than was ever believed possible could be done for fellow human beings with multiple handicaps. Educators like Itard and Seguin from France and Howe in the United States showed the way as long ago as the nineteenth century. They epitomized the “developmental principle.” That is, they believed in the capability of a mentally handicapped person to grow and develop if given the right environment. Wolfensberger (1972) notes that such an environment requires a profound belief by others that the person is not an inanimate object, who cannot feel or understand, a holy innocent, an object of charity, pity, or ridicule. A handicapped person is a human being worthy of all the dignity given to nonhandicapped citizens.

Tied in to the developmental principle is a belief in the “dignity of risk,” according to Perske (1972). Put simply, this means that just as nonhandicapped individuals must learn through experience and have a right to learn through risk-taking, it is vitally important not to encapsulate a handicapped person in an overprotective, artificial world. Such a world may accomplish the goal of protecting the person while depriving that person of the experiences that go with living and learning. Most children learn that matches are hot while experimenting with them. They learn that a dog can be mean when they get too close to the bone the dog is chewing on. Robert Smithdas, one of the speakers at the National Vocational Rehabilitation Counselor Conference held in October, 1975, put it beautifully:

I think that I was very fortunate, because while I was growing up I was not inhibited by my family or teachers in doing the things I wanted to do. If I felt like wandering around my home or the neighborhood, my family permitted it. At the first deaf school I attended, all of the teachers were concerned that I would wander away from the premises, but that didn’t keep me from wandering about the grounds as much as I pleased. Later, when I went to the Perkins School for the Blind, where I attended high school, all of the deaf-blind children were protected by their teachers and carefully guarded against anything that might cause injury. I rebelled against having a constant companion, because I felt that I was capable of taking care of myself and I didn’t want a companion when I wanted to do certain things. I feel that this type of supervision has changed to a great degree in many of the schools that have special departments for deaf-blind children. Today, teachers are beginning to realize that the way to help children to grow is to encourage their curiosity and help them experience as many things as they possibly can by touching them, tasting and smelling them, or by exploring them in any other way that seems feasible.

The Principle of Normalization

In the 1950s a group of parents in Sweden became upset about the failure of the government
to respond to their needs and to those of their mentally retarded sons and daughters. From their frustration came a principle which is so simple that it seems almost silly. It is the "principle of normalization," which means, according to Nirje (1968), "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society." They were not native parents who wanted to believe that their kids would be cured, they knew mental retardation is a lifelong condition. They just felt that if their children could live with normal people, in normal communities, under normal conditions, they would have more stimulation and more developmental growth experiences and, therefore, could come as close as possible to achieving their maximum potential. For example, normalization means things like going to bed at the same time as younger brothers and sisters, celebrating holidays as everybody else does not on a different day because the institution staff will not be there on the Fourth of July or Christmas. It means being treated as an adult if the handicapped person is one. It means enjoying the company of members of the opposite sex and a normal rhythm of life so that when handicapped persons get old and want to stay in familiar surroundings, they can and no one can force them to live in a nursing home as long as they can care for themselves with a little help from a friendly visitor or Meals on Wheels.

Those are some of the reasons why normalization is called a "powerful process" or "deceptively simple." The effects of the process are so common that most people take them for granted. Even the way people talk becomes important. If I am called Mr. Skarnulis, then why is my mentally retarded adult friend not called Mr. Smith? Does an institution called Hope Haven really offer hope? Is it a haven? If it is, how are mentally retarded people likely to be served in such an environment? Are state regional centers normal? Are they called hospital-schools? Are they truly either hospitals or schools? What does separating children of normal intelligence from mentally retarded children really accomplish? Someone has asked if special education in schools is either special or education. Is it a euphemism for segregation of children who are different?

Obviously, there are times when people with special needs cannot possibly be treated as though those needs do not exist. Normalization means making available conditions as nearly normal as possible, and dignity of risk means reasonable risk.

If parents and professionals accept these principles, they must use judgment that enables them to differentiate between limits that are set for handicapped people and the limits that they set for themselves.

The Residential Assumption

In 1968 some parents, politicians, and professionals in eastern Nebraska decided to attempt what the parents in Sweden were doing. They designed an entire system of services based on the normalization principle. They begged or borrowed what they needed to open a vocational center, a day-care center, and a group home, and they later added recreation programs, medical services, and transportation. That was the beginning of what is now the Eastern Nebraska Community Office of Retardation (ENCOR). Today ENCOR has a federal, state, and local funding and is providing a multitude of services to over 1,000 people per month.

I served as ENCOR's director of family resource services for a year, helping to set up or expand speech therapy, counseling, volunteer programs, recreation, and other psychological and medical support services. It was very exciting. A young organization with very idealistic, committed employees, held together by a common philosophy. At the end of the year, I was asked to manage the residential services division. My years in the residential services division impressed on me the need to begin questioning some of the things the organization was doing while purporting to adhere to the principle of normalization.

Parents seldom came to me saying, "I need my boy out of the house a few days a week." They came to me saying, "How can I keep him from scratching his sister?" or "We haven't had a chance to join a bowling league or spend a weekend alone together since Jimmy was born." I began to wonder if ENCOR were not guilty of overkill. These families did not need residential services; they needed ordinary help just as all people do. ENCOR established expensive group homes, expecting people to fit into them. Solutions were being defined in terms of available resources instead of unmet needs.

We, at ENCOR seemed to be assuming, for example, that just because a person is mentally retarded, that person must need residential services. We all grew up hearing things like "That Scott girl is going to be put in an institution." "Why?" "Oh, she's retarded, you know." What does "retarded" mean? What does "deaf-blind" mean?"
mean? For that matter, what does “residential services” mean?

When people have needs that cannot be taken care of in their own homes, they may have to live somewhere else until the need is met. A college student lives in a dormitory for four years; a child who is being abused must be taken from his or her home; a sick person goes to a hospital; and if I beat my wife, I either go to jail or a mental health facility. There are indeed legitimate reasons for all persons to need residential services. However, most people would not dream of saying, "You have normal intelligence; therefore, we are taking you from your home." It is really no less ridiculous to say, "You’re deaf-blind; therefore, you must leave home." What is accomplished by removing the handicapped from their homes? They do not become "un-mentally retarded" or "un-deaf-blind." No magical cures are being performed.

Degrees of Restrictiveness

Three indexes are useful in determining the degree of restrictiveness of residential services for handicapped citizens: the size of the residence, the distance from the family home, and the length of stay.

The Size of the Residence

The size of the residence is determined by the number of unrelated persons living together. A person with special needs usually requires extra attention and hard work. If that attention and work must be provided by sacrificing time spent with other people in the household, there is bound to be conflict. If a handicapped person has to compete for attention with other handicapped persons, only the most aggressive reap rewards. Even in a person’s natural home, if parents care for both their handicapped child as well as their normal children, and the handicapping condition is a severe one, someone will have to sacrifice. The parents will burn the candle at both ends, thereby jeopardizing their physical and mental health; the handicapped child will be deprived of necessary educational or medical help; or the brothers and sisters will not receive the nurture of their parents, therefore, failing to develop appropriately or harboring resentment against their handicapped sibling.

It is important to bear in mind, however, that at least in the natural home the parents have invested in the outcome of their work with the handicapped person. They care what happens. The most dedicated staff members in the smallest residential facilities are never quite able to replicate that sense of commitment. It is a far different thing to be awakened at two o’clock in the morning by the crying of one’s own child than to be awakened by someone else’s. One’s voice will be stronger when speaking with doctors, teachers, and welfare workers if the person being discussed is one’s own son or daughter rather than a client, a patient, or a student.

Distance from Family Home

It is not at all uncommon to see family groups which are close to one another slowly deteriorate when family members move away. At first the visits are frequent and intense, but interests change and loyalties become blurred, influenced by economics and logistics. When parents, brothers, and sisters have to spend time and money traveling to and from distant residential facilities, it is no wonder that family ties break. The decreasing frequency of visits becomes a source of guilt for family members. They feel compelled to rationalize those feelings by insisting, "He is happier with his own kind," "She gets special training there," "It’s a school," "Those people understand children like this better than I do," "This will only be for a little while."

There is always a modicum of truth in the rationalizations. It may be true that some of the staff members have special training, but the specific skills required to serve handicapped persons need not be mystical. Fancy equipment or buildings are not required; the skills can usually be taught without a great deal of effort. While, it is true that families intend to have their handicapped children out of the home for a short period of time, there are rarely "contracts" which require progress in a reasonable amount of time. More often than not the handicapped person stays in the residence indefinitely. While it is true that some training occurs in residential settings, the bulk of the education and training that takes place is performed during the school day; and the residential staff are seldom highly skilled individuals whose primary purpose is to provide treatment and education. They are usually ordinary people who live with handicapped individuals and relate effectively to them. In any case, common sense says that even a handicapped person cannot possibly be "programmed" 24 hours a day.

Time Spent in a Residential Facility

The longer a person remains out of his or her home, the more difficult it is to get back in again.
This is true of both the family home and the community. Things change. Neighbors move away, buildings are torn down, and the whole spectrum of sights and sounds, of tastes and smells, can be altered dramatically in a short period of time. It is difficult enough for those who are free of handicapping conditions to cope with such changes and more difficult yet to adapt to the new experiences. But if one has been removed from a community for a period of years, the difficulty of reintegration is magnified. Unfortunately, most residential services claim that they exist to prepare the handicapped person for reentry into this normal environment. Is it really possible to reproduce all of the sensations, knowing which neighbors are my friends, which dogs bite, where the curb is?

Keeping Solutions Simple

Crawford (1976) tells the story of a very frank director of a service for the retarded in San Francisco in 1968 who said to a naive student, "Look, mothers need" diagnosis and assessment of their retarded children as much as they need a hole in the head; they have been told many times what is wrong, what they need is services." It is services that are required, says Crawford, not surveys, committees of inquiry, or other expensive excuses for inaction.

The parents of six children whose ages range from one to twelve cannot become terribly excited when asked to follow through on physical therapy or speech therapy training programs with their handicapped three-year-old child. Further, it would not be surprising to find evidence of stress in such a family, nor should it be puzzling if they request removal of the handicapped child from the home.

What parents need are babysitters or housekeepers who can dust, scrub floors, wash dishes, and help with the handicapped child. They need money to construct ramps into the home for their kids' wheelchairs; to install support bars in the bathroom and hard-of-hearing handsets on the telephone; to purchase multiaction toys to stimulate tactile sensory perception; and to help with medical bills and transportation to and from hospitals and community agencies.

We can see how a system might work if we follow some of the reasoning outlined above in a typical situation. A child has just been born, and the parents have been told that the child has a serious physical or mental problem. While the medical needs are being met, the nurse, doctor, or visiting nurse association may refer the parents to a local parent group or agency which serves handicapped youngsters. The agency sends someone to the home. Arrangements may also be made for parents who have been through the same experience to visit their home. In such cases the representative of the agency should not ask the family to come to an office. All people feel more comfortable talking about their personal crises when they do it on their own "turf." Home visits also help distinguish the person being served from the one whose job it is to serve. The family members are encouraged to explain what they want or need in their own words. They are asked what they need in the way of help with money, transportation, medical equipment, and so on.

In some cases the parents have less difficulty accepting the fact of their child's handicap than do extended family members, such as grandmothers, grandfathers, aunts, and uncles. It may be that those are the ones who need counseling. It should be made clear at the outset that the family makes the decisions and that the agency is just a partner in the process. What the parents perceive to be needed, not the perceptions of other people, will determine their ability to help their sons or daughters. Because most people cannot put their needs into technical jargon, it may be necessary to help them translate their needs into suitable language. For example, parents may not have the vaguest idea about funding sources, such as supplemental security income, Title XIX, and the like, but surely someone who is knowledgeable can understand the parents' financial needs and find existing sources of funding to fill those needs.

When families come to agencies such as ENCOR with specific problems that need specific solutions, the solutions should be kept simple. The mother is tired? She should be given help in the home so that she can have time for rest and relaxation. The parents do not have time for recreation and social life? Then they should be provided with babysitting services or a weekend helper who can take care of not only their disabled child but also their normal children. The neighbors are giving them a rough time? A staff member should meet with the family and neighbors and help explain the problem. If that does not work, the staff member should contact whatever local authorities will be necessary to prevent undue harassment. This does not mean that agencies should simply give the families this kindly advice—it means that the agency should do it!

If dad is out of work, the agency should help him find a job.
Thousands of prosthetic appliances and educational toys are available in special schools or hospitals. Many are inexpensive; others cost a lot, but all could be lent to families. A carpenter working with a physical therapist, occupational therapist, speech therapist, or teacher can work miracles with scraps of wood.

If parents are concerned about who will help their child if they should die unexpectedly, they need an attorney, perhaps a trustworthy insurance agent, or a banker.

If toilet training is a problem, simple bells, buzzers, lights, or warmth-detecting devices can be used with great success in alerting the parent that the child has toileted or needs to. Using such simple behavior-shaping training, parents can quickly and permanently resolve the problem. The devices can be reused, and training for parents is not difficult.

If a parent does not have enough time for the other children, timesaving appliances might help. A washer, a dryer, a dishwasher, a second car, or even bus tickets could mean the difference between keeping the handicapped child or placing the child out of the home.

Mom, dad, brother, or sister has to have a serious operation and cannot care for the handicapped child as well. The agency should place someone in the home to help out.

If there is no way to care for the child during the summer months while both parents are still at work, the agency can hire and train someone to provide that service during the summer, or arrange for normal preschool and normal day-care programs to admit the person with additional staff help or additional funds to make up the extra costs. This is something that could be done with a group of families with handicapped members.

When a handicapped person requires more than usual educational help, the agency can bring a tutor into the home, perhaps a high school student who would be willing to tutor on an hourly basis. I would strongly recommend against tutors who simply donate their time because such arrangements usually do not work out to the advantage of the family involved.

If the people helping the family are paid by the agency and the family cannot get those people to do what needs to be done, the agency should pay the family and let the

Families should be treated as if they are doing their best to help prevent the rest of society from having to pick up the tab for their children's problems. They are not asking for charity. They know the problem and the solution: they need someone to do what they obviously do not have the time, money, or influence to accomplish.

One of the unfortunate evils of state and federal funding today is the tendency to deal with discrete, isolated problem areas rather than allowing local agencies to use funds in a creative, tailor-made fashion. For example, according to Edward R. Goldman, "Pennsylvania received $55 million in federal funds for medical assistance benefits in fiscal year 1973, almost three times the national allotment for all state grants for developmental disabilities, community, and institutional programs. Today it is estimated that it will cost $1 million to maintain each resident of a public institution throughout his or her lifetime. It should be fairly obvious from that figure alone that the money is available to help families if such help is made a priority."

Summary

Those who have to set up residential services can learn from ENCOR's experience. Some people said to us, "You can serve the mildly retarded, but you can never serve the moderately, severely, or profoundly retarded." However, the bulk of our system now serves severely and profoundly retarded people. Most moderately and mildly retarded people have become independent or semi-independent. The scoffers also said, "You will never be able to serve the really problematic people with maladaptive behaviors, the ones who beat their heads against the wall and bite people and kick and scratch and hurt themselves." But we set up a behavior-shaping program and brought all of the children back from the institution to go through
that program. We have since closed that institution. Then they said, "You can’t serve kids that are medically fragile, near death." We set up a development maximization unit and have been serving them regularly and moving them back into their own homes of our regular residences.

The doubters also said, "You can’t serve small numbers." Last year we brought 100 people into our residential system. They said, "You can’t do it cheaply." But last year again, in spite of bringing in 100 new people, in spite of all of the resulting starting costs, in spite of a 10 percent cost-of-living wage increase to our staff and 15 percent inflation rate, we were still able to reduce our total costs to a level below what they would have been if we had used group homes as our only option. They said, "You can’t serve legal offenders." So we set up a program for legal offenders called the "Structured Correctional Program." This year those same people said to us, "You can’t do it without money." This time they were right. It cannot be done without money.

References


Not many people are aware that California has a very special population in its state facilities: those with developmental disabilities. Developmental disabilities are attributable to many causes: cerebral palsy, epilepsy, mental retardation, or any neurological condition that is closely related to mental retardation. These disabilities, which cannot be cured, are a substantial handicap. Those who suffer from them cannot benefit from the social, educational, vocational, recreational, and medical resources that nonhandicapped individuals have access to in the community. State programs emphasize placing clients with a family or into their own homes, but sufficient resources have not yet been developed to allow such placement into the community. Whatever the limitations, though, the emphasis is always on providing developmental and habilitative programming.

To best meet client needs, organized treatment programs are used. Clients with similar characteristics, problems, and needs are grouped together so that all the children who are deaf and blind usually live in the same residence. Then the residential staff can sign to them, and everybody learns how to sign. At Fairview there are currently 1,700 clients in 44 living units. Those clients represent the whole spectrum of problems and needs found in the developmentally disabled: 88 percent are severely or profoundly retarded; 60 percent have no speech, and another 27 percent have major speech problems; 33 percent are not toilet trained; 55 percent must be bathed, and another 24 percent need considerable assistance in bathing; 38 percent must be dressed, and another 20 percent need assistance in dressing; 10 percent are blind, and another 10 percent have limited vision; 5 percent are deaf; and 4 percent have limited hearing. This is a population with very special needs.

Measurable development is always the objective for these clients. Is the methodology correct? Are the programs developing those skills that involve physical, intellectual, and vocational functioning as well as reducing the frequency and severity of acute and chronic medical conditions? The process for accomplishing these objectives involves providing a motivated, trained, multidisciplined staff for all the treatment programs and through that staff providing an active habilitation program for a normalizing environment. Those individuals providing services in special programs come from many disciplines: audiology, speech pathology, education, library services, music, art, dance, occupational therapy, physical therapy, recreation, religion, social work, psychology, nursing, all the activity therapies, medicine, and nutrition. All clients receive these services if they need them. The system used to provide these services is called the individual client case management program and plan. Everybody gets together and lists the needs of the client. An individual client assessment is written to identify problems and needs. Then treatment objectives are established, stated in measurable, observable, time-limited terms. After the needs assessment has been made, a program and plan are developed to meet the objectives.

The deaf-blind project is a supplemental service to the individual case management program. The supplemental services can involve 15 minutes, an hour, 2 hours, or 6 hours. Only the interdisciplinary team can decide. The first step, of course, is to document that there are residents who are deaf and blind in the potential project. Recognition of such impairments may come through the clients' annual physical examinations, but more often it comes through the observations of the interdisciplinary team itself: someone says, "I don't think Frank is really hearing you." This observation triggers an evaluation request to the speech pathology and audiology services office where a certified audiologist and a speech pathologist do the evaluating. They can tell whether there is a real problem and whether the client is eligible for the deaf-blind project.

After the eligible population is identified, the money must be budgeted. A teacher costs almost two and a half times as much as a teaching
assistant, and a good paraprofessional or teaching assistant is just as competent in most cases as a teacher. Then comes a real budget crisis: whether to hire two teachers or five teaching assistants. The staff of Fairview State Hospital has gone the latter way, and I think that the choice has been successful. The interdisciplinary team then groups the project population in accordance with the individuals’ needs and plans the program for the year.

The children at Fairview present such an involved total picture that it is very difficult to evaluate them. As a result, it becomes essential for the representatives of all disciplines to combine their efforts toward the goal of complete understanding of the children, their situation, and their growth. The group approach, which is necessary for evaluation and assessment, leads to consistency and a more complete cooperation, coordination, and communication among the adults coming into contact with the child. Since consistency is essential to develop the child’s sense of security, we strive for the maximum consistency in our expectations, demands, discipline, and reinforcement. Interventions and strategies in the education program are based on the individual client’s needs in the areas of communication, mobility, training, social skills, and self-concept development. This program supplements the regular programs.
The Care of a Deaf-Blind Resident

Ann Fox
Assistant Chief, Central Program Services
Pacific State Hospital

A state hospital exists to provide the everyday care and training necessary for the developmental growth of its residents. The experience, physical condition, and intelligence of each deaf-blind resident correlate with his or her emotional and psychological preparedness to undertake training are diagnosed by a team of specialists. The specialists, then, prepare a written plan describing specific objectives to be met within a described time frame. The content of such plans is never intended to be restrictive. These plans are used only by instructors who are equipped by special training, general background, and personal resourcefulness to adapt them to meet the special needs of the individual deaf-blind resident. Each instructor continuously remains alert to add new experiences and new opportunities to each plan to broaden the development horizons of the deaf-blind residents. The residents are encouraged to remain alert and to find significance in all stimuli from their immediate environment.

Generally speaking, much more time is spent explaining and demonstrating the techniques being taught to a deaf-blind resident than is spent training. As a result, the length of time needed for training a deaf-blind resident is greater than that needed for the training of a hearing-blind person. The limitation of communication is a prime consideration in estimating training time. Every effort is made to determine the extent of a deaf-blind resident's ability to transmit and receive information through the method of communication being used. Frequently, an instructor finds it helpful to learn the method of communication the deaf-blind resident has already established before the instructor can formalize communication skills and language development skills.

The void of experience that deaf-blind residents usually exhibit when beginning to learn requires that the instructor ensure that the residents are aware of those objects in their environment that are useful for developmental growth. The deaf-blind residents must be given the opportunity of tactual exploration—for instance, the trees at the lake or the donkey at the farm. Allowing the deaf-blind residents the time for such experiences represents a major contribution to their overall adjustment and knowledge and is just as important in terms of their goals as actual instruction in the use of the cane.

Instructors find that some deaf-blind residents need a great deal of encouragement in order to enter into a travel training program and to continue in it. Generally, independent travel is a new concept for deaf-blind residents entering a state hospital. It requires a great deal of ingenuity, patience, and understanding on the part of the instructor to help the deaf-blind resident appreciate the value of independent travel and to accept the challenge of learning it. Encouragement consistent with the progress of the deaf-blind residents will give them the motivation to continue in spite of any discouragement or lack of belief in their ability to learn.
The Deaf-Blind Program at Porterville State Hospital  
Joan Clinton  
Assistant Chief, Central Program Services  
Porterville State Hospital

When the opportunity to describe the deaf-blind program at Porterville State Hospital was extended to me, one of the questions that immediately rose in my mind was how to explain adequately what goes on in state facilities so that nonhospital people could see that we do offer a positive and necessary service. Many people think that state hospitals are end-of-the-line institutions and that children are put in there to vegetate. Such a concept of a state hospital is wrong.  

First, let us consider the relationship of the state hospital to the community. State hospitals are to provide service to the community by offering a limited term residential program designed to prepare the child for placement outside that institution. This probably came as quite a surprise to the many people who think of a state hospital as a place to which youngsters are sent never to be seen again. As I stated earlier, nothing could be farther from the truth. We are just a way station where youngsters can receive the developmental training they need to equip them to become contributing members of the family and the community. The state hospital is an alternative placement for those who need it. The ultimate goal is to move each developmentally disabled child out of the state residential facility system and into an appropriate community setting. Obviously, this is a more achievable goal for some than it is for others; but that fact does not relieve us of the responsibility to provide services toward the goal of community placement for all residents.  

Since our eventual goal is to see deaf-blind children in an appropriate community setting, a challenge exists for those who make up the child's family and community environment. The programs provided by a state facility are carried out in vain if the community does not respond to the need to provide proper placement in which everyday living, medical, educational, social service, vocational, and other related rehabilitative services are available. All members of the community are obligated to provide the optimum environment to our youngsters.  

State hospitals offer programs as part of a continuum of state services for the developmentally disabled under the provisions of the Lanterman Developmental Disabilities Services Act. Services are offered until such time as the family and community, working through regional centers for the developmentally disabled, have developed the resources needed for the individual child. Until that time, state facilities design their programming around the child's overall needs. We are here to serve the parents and the other community members. Competition with or isolation from the community is never our intent. Our aim is to function as part of the team effort in which the family, the community, and the state work together to provide what is best for the child. It would be very helpful to those who are not familiar with state hospital programs to visit us. We would like to discuss with you what it is we do and even to get ideas as to how we can do it best.  

As part of the efforts of Porterville State Hospital to comply with the standards of the Creditation Council for Services of Mentally Retarded and Other Developmentally Disabled (or the Joint Commission for Creditation of Hospital Facilities for Mentally Retarded [JCHFMR], as it was formerly called), we seek to meet over 600 individual standards. There are thousands altogether, 600 of which are related to the care and treatment of the mentally disabled in residential facilities. In addition, we are bound to adhere to California's Welfare and Institutions Code. A quote from the JCHFMR administration's manual summarizes our challenge:

The primary purpose of a residential facility for the mentally retarded is to protect and nurture the dignity, health, and development of each individual requiring 24-hour programming services. Inherent in this commitment is the responsibility to provide those experiences
that will enable the individual to first of all develop physical, intellectual, social, and emotional capabilities to their fullest extent. Next, to live in an environment that is conducive to personal dignity while in that residential setting. And third, to continue development of those skills, habits, and attitudes essential to adaptation in contemporary society.

Our residents, even though each has special needs, shall have the same rights to opportunities for growth and development as any other human being. Each resident has an inherent right to fulfill his or her full potential. It is possible to help all citizens who are labeled developmentally disabled to lead rich, dignified, honored and socially enhanced lives regardless of the degree of disability. To this end we recognize the need to consider each of our residents as individuals with individual needs. You simply cannot group people together and say they are all alike. You cannot set group objectives; you can have group goals, but each person needs his or her own objective and his or her own treatment plan.

Porterville State Hospital has nine treatment programs. Each of them is geared to meet the specific needs of the 125 to 250 residents assigned to us. Each treatment program is responsible for the total care and habilitative treatment of its residents in areas such as nursing care, developmental training, social services, habilitation therapy, education, and psychological services. In addition to these treatment programs, we also offer medical activities, including a laboratory, a pharmacy, an x-ray unit, electroencephalogram, electrocardiogram, physical therapy, and dentistry. The hospital also offers, through centralized programs, recreation and vocational rehabilitation services, a camping program, a foster grandparent project, a barber, a beautician, volunteer services, chaplain services, and, of course, educational programs.

When a child is admitted to a facility, a complete evaluation is made to determine the child’s physical and medical condition and to assess his or her needs for psychology, social work, speech, education, and vocational rehabilitation services. Using these evaluations, a treatment team composed of management and treatment personnel designs an individual program with very clearly defined objectives. This basic approach is augmented by the many services referred to earlier, including recreation, camping, foster grandparents, social relationship provided by the volunteers, and many other activities that help give the children a normalized life-style. Recreation services offer opportunities for swimming; dancing; participation in the special olympics and holiday celebrations; and trips to concerts, plays, movies, zoos, Disneyland, Magic Mountain, rodeos, circuses, picnics, beach parties, mountain excursions, and sporting events.

Vocational training is offered through a series of graduated programs. The vocational preparation program starts on a very simple level, such as learning to come to work and learning to attend to a task. From there the participant progresses to prevocational training, a work activity center, hospital skill training, community skill training, and community employment. Individualized attention is available through the foster grandparent project. This is a federally funded program in which senior citizens spend time with residents on a one-to-one basis. It is difficult to determine who benefits most, the children or the foster grandparents.

Volunteer services offer a friendship program in which concerned citizens can sponsor one or more residents who do not have contact with their families. Volunteer services also provide a means for the community to provide many extras, such as bedspreads, drapes, or toys. All of these treatments and other services mentioned are available to our deaf-blind residents, as they are to the nonsensory handicapped. Our deaf-blind children are not isolated: they are part of our total program. Their lives are more normal when they experience life with everybody else.

To a state facility children are not just numbers. They are individual people with individual needs. We try to meet these individual needs by bringing together specialists in an interdisciplinary team to plan programs for the care and treatment of the children.

Because our residents, even though they are in an institution, need to learn about family life, we try to give some training in what it is like to eat in a family situation. Their meals are served family style. The residents set their own table; they dish up their food; and they sit down as a family to eat. This is a part of their daily training, along with other daily activities such as making their own beds.

The educational experiences are many and varied. For example, because learning to be mobile means learning to move independently and because balance has to be learned, the child is taught to develop the ability to maintain balance. Another example is audiological training. Preliminary audiological screening aids the teacher in determining appropriate auditory training; the children learn to listen, to attend to sound, and to identify sound.

Educational activities are not confined to traditional classrooms. Aquatic skills can be used to
learn...interaction with others; the feeling of trust, and how to swim. We have five pools at our hospital. Each is designed to provide for a different need. We have a pool that is one foot deep and one that is 12 feet deep and has a diving board. We also have a therapy pool. All the pools are heated and chlorinated. Our parents built those pools for us. They raised the money, donated the labor, and produced a beautiful facility. It is because parents love and care that we are able to provide many of these services.

Basic mobility skills and balance lead to more complex activity. Learning to climb, gaining confidence in walking, developing spatial orientation in a confined area—these are all important to the blind child. Although it is important to the child to learn to walk down stairs, or climb the jungle gym, or roll about, or just have fun on an air mat, there is more to guiding a child to a full life than these traditional habilitation activities. There are many normal experiences provided in order to give the child a fuller life. We try to offer students the opportunity to learn how to get around and to have normal experiences. The hospital is really a miniature city. We have our own transportation system. We can go any place on the approximately 900 acres. We have ministers who provide religious services geared to the children's level.

Programming like ours does not just happen. Careful planning and utilization of resources is necessary. Planning is the province of administration. I am an administrator, and I had to know myself well before I could start carrying out programs and arranging for other people to help. Although these remarks are primarily for administrators, they can also apply to home or classroom situations. I am going to omit those obvious administrative paths like personnel management, physical responsibility, and other aspects of maintaining a program. Instead, I am going to talk about policy making and planning. Though not covering all aspects of administration, this discussion might provide some ideas and an opportunity for others involved in the treatment of the deaf-blind to do a little self-examination.

First of all, before a program is designed, an administrator must understand clearly what it means to be an administrator. Traditionally, administrators are thought of as managers or facilitators, people who see that things get done. That description is accurate, but it certainly does not present a complete picture. The literature of the past 20 years indicates that administrators must also formulate policies and provide leadership. Because if administrators do nothing but maintain, they will create complacency and a static, inbred program. We must formulate and shape and refine before we execute. We must be more than just housekeepers.

But before we can provide effective policies and leadership, we must establish a system of values. Our powers and responsibilities should be balanced with moral principles. It would be disastrous to let administrative techniques and processes dominate to the exclusion of a basic philosophy based on public interest. Value clarification does not come easily. One does not just sit down one day and formulate a value system. It is not that easy. It is a long, arduous, and sometimes painfully introspective task. Few of us are brilliant enough to formulate original theories or statements of a profound philosophical nature; but many administrators have already done it, whether they realize it or not. Administrators who have not already done it should start reading, studying, and comparing.

There are many public administrative philosophers and essayists. The thoughts of authors like Drucker, Fawn, Dewie, Limbrock, Mills, Devore, and Mumford are available in any good library. Our institutions of higher learning offer many courses in philosophy, social sciences, and administrative policies. Most administrators have been exposed at least to some of these studies, but it is a rare person who cannot benefit from continued study and reevaluation. Complacency leads to mediocrity.

Once a basic philosophy is formulated, the next step is to involve the staff. They should be allowed to develop a program's basic philosophy and intended policies. Not only will there be a broader input, but also the people running the program will be more personally involved, and this will lead to greater interest and commitment to success on their part. Out of such discussions come the goals, which in turn determine the objectives. Specific objectives can be best determined by first assessing the needs of the children. How well do they move about? Can they communicate with others? Do they have the daily living skills needed to eat, to dress, and to toilet? Do they have a concept of self? How well do they socialize with others? Those are all basic skills, ones that are necessary if a child is going to achieve anything beyond mere existence.

When setting up objectives, one should remember to include the entire family unit in the needs assessment. It is a good idea to establish an objective that involves family members in the development of the child's treatment program.
They have a vested interest; they should help plan the treatment. Family members should be able to participate in treatment activities, too. The family may also benefit from counseling or other supportive services. Some parents have difficulty accepting the fact that they have deaf-blind children; they may even have difficulty understanding or even associating with those children. Administrators must make provisions for involving the families and keeping them in touch through newsletters, telephone calls, progress reports, and so forth.

The outlook of the needs assessment should not be narrow; resources are more than staffing ratios, buildings, and money. There are experts and consultants available with a wealth of talents and interests. One of the hospital's most valued resources, as I have said, is the parent: Parents and parent groups provide many things, not just physically and monetarily. They also provide advice and concern, and they pressure the Legislature for better conditions.

Following the needs assessment comes the time to plan activities and evaluate procedures. Planning is never something that should just happen. If a situation calls for crisis management (the development of a plan as an expedient solution to an immediate problem), the result will be an establishment of a haphazard approach to planning so that programs do not just grow and grow with no guidelines or purposes. As the trite but true little saying warns, "Failing to plan is planning to fail."

The next step is to start doing something, to put all the mental exercise into action. After initiating programs, administrators must follow through with planned activities, but only as long as they are producing the desired results. If the planning was done well and baselines were established, data and observations will tell whether or not the plan is accomplishing what it was established to do. Planning and evaluation procedures should take place at the beginning of activities rather than later so that relevant and necessary data are available throughout the process. Nothing could be worse than letting someone else's data, which just happens to be available, determine one's appraisal procedures. It should be the other way around: the evaluation program should determine what data to collect.

After examining the results of a program, the administrator should look again at the objectives. Objectives that are met may need to be replaced with further objectives. For objectives that are not met, it must be determined whether the objectives were inappropriate or the methodology was wrong. Whatever the answer, the cycle starts again: establish new objectives and begin planning.
The Experiences of Benhaven and Their Application to the Deaf-Blind

Amy L. Lettick
Director, Benhaven School/Community

Benhaven is a relatively small educational facility with sections located in New Haven, East Haven, and North Haven, Connecticut. In the New Haven section, there is a large house which has been converted into a school; behind that is a regulation-sized gymnasium. Seven miles away there is a 35-acre farm on which, in addition to farm buildings, there is Northside, the first house of our proposed village of eight houses.

Benhaven's children—even though they may also be blind or deaf—are quite different from the ones served by the deaf-blind centers. Their problems are not the same as those of a deaf-blind child; however, some of our findings at Benhaven may be applicable to deaf-blind children, too.

For some people it may be a problem to distinguish between someone who is mentally retarded and someone who is autistic. The difference between the two types of individuals is basically that retarded individuals have a level ceiling capping their potential to develop. This means that a ten-year-old mentally retarded boy with an IQ of 50 will be very much like a five-year-old boy in all areas: speech, social development, and cognitive ability. If one treats him as a five-year-old boy, he will get along very well. This is not so at Benhaven. Instead of a level ceiling of ability, the children there display a series of peaks and valleys described by some as "islands of intelligence in a sea of retardation." Another difference between the retarded and the autistic is that retarded individuals are not necessarily impaired in their social development. One frequently sees little groups of retarded children being taught by one teacher. They can function as a group. The autistic cannot. The mentally retarded can also have normal language development. Again, the autistic cannot.

Neurologically impaired individuals are different from mentally retarded persons in that the neurologically impaired are assumed to have had a potential for normalcy until there was some kind of accident or malfunction occurring in the area of the central nervous system. Neurologically impaired persons can be identified by the disparity between some of their handicaps and some of their strengths. There is often more than four years' difference in the capabilities of such children, for example in the use of language and the fine motor skills. Neurologically impaired individuals can have problems in their motor skills, whether gross or fine. They can have problems with their memory, short-term or long-term memory, or in the sequencing of any kind of visual or auditory tasks. Neurologically impaired individuals often are hyperactive; they are easily distracted; they have a very short attention span; they have very poor communication skills; poor perceptual skills; and generally an impaired ability to learn. Here, too, however, there does not necessarily have to be impairment in the social development or in the language: for while the perceptual skills may be damaged, they are not necessarily so. There is a great range of disability in a neurologically impaired child. Of course, we must always take into consideration that there are children who have multiple handicaps, such as neurological impairment and retardation or neurological impairment and autism.

Classically autistic individuals usually have made their impairments known by the age of two and a half or three. There are three major characteristics which are always seen together. The most important and the most damaging is the inability to relate properly to people, places, and events. One frequently sees little groups of retarded children being taught by one teacher. They can function as a group. The autistic cannot. The mentally retarded can also have normal language development. Again, the autistic cannot.

Ritualistic behavior involves doing things which everyone does at times except that autistic persons combine activities in a fixed pattern which they obey compulsively and which has no apparent meaning or purpose. For example, an autistic youngster might always enter a room by sliding one foot forward as though he or she were testing the ice on a pond, then step into the room, briskly walk to the same three pieces of furniture...
The difference between ritualistic and bizarre behavior is that, while portions of the ritualistic behavior would have a purpose at the appropriate time in a normal person's life, bizarre behavior is totally purposeless. For example, one characteristic behavior of autistic children is the waving of the fingers in front of the face; one cannot be sure whether the individual is looking at the fingers, beyond the fingers, through the fingers, or looking inward. Another example is biting the palm of one hand in the same spot continually. Although many neurologically impaired and retarded youngsters also have bizarre or ritualistic behavior, the act of finger waving appears only in autistic people. In summary, then, the neurologically impaired or retarded whose behavior is similar to that of the autistic could be called autistic-like; however, to fit the pattern of classical autism, they must not only possess the characteristics of poor social relatedness, poor communication, and bizarre behavior, but also display no evidence of true mental retardation, real neurological impairment, or abnormal development of motor milestones.

How do the autistic and the neurologically impaired resemble blind and deaf people? Here is the one obvious way: they cannot process messages which come through the sensory organs. The reason for the disability, however, is different in each case. The problem for the autistic and neurologically impaired is an inability to process the information that the sensory organs send to the brain. This is a far different situation from that of the blind or deaf person who has a potential for language far beyond that of autistic children. Another difference is that although deaf persons' language would not necessarily be normal, they have a potential for language far beyond that of autistic children. And their social awareness and social development may be far more normal than that of autistic or neurologically impaired individuals. This social awareness will make a difference in where one places a handicapped child.

An autistic child will have no understanding of a handicap in another person. A deaf-blind child might be able to understand another person's needs.

Another difference between the autistic and neurologically impaired and the deaf-blind is the amount of independence in mobility that one can expect from a sighted autistic child. In most cases, a sighted autistic child, unlike a blind child, can move around in an environment with safety. The same is not necessarily true in terms of the hearing. There are many autistic children who cannot understand environmental noises; therefore, the sound of a horn or a bell is just as useless as a warning to an autistic child as it is to a deaf child. Again, there are different levels of handicap and disability, so what applies in one case may not apply to all.

Benhaven is a private, nonprofit school for the deaf-blind. We have a population of 38 children, adolescents, and adults. More than a third of the 38 are over sixteen years old. Nearly all of the students were considered hopeless. We are the last resort for children before a mental hospital or worse, the first step out of one.

The philosophy that has guided us since we opened our doors in 1967 has shaped our progress:

- Benhaven believes that special education, not psychotherapy, is what our children need. We teach; we do not treat.
- We believe that active help rather than passive love is what changes children. It is not enough to offer children compassion and understanding. We must channel our love into constructive, concrete action.
- We believe that our children need order, structure, and stability in their lives, with a goal of independence on whatever level can be achieved and maintained in view of the individual's handicaps.
- We believe that an intensive, driving, dynamic program involving continuous measurement, diagnosis, and adjustment of techniques is the force that propels our children on the roads we would have them travel.
- We believe that we cannot wait to build relationships with children whose inability to make relationships has brought them to us. Instead, we must begin to work with the child immediately, keeping in mind the idea that through work relationships will be formed.
- We believe that there is no one way that will help every child. We must employ all methods...
and consultants that will be of assistance in working with the unique problems presented by each child; therefore, we use direct teaching, team teaching, behavior modification, restraints—anything that will work.

- We believe that sometimes extreme disability requires extreme measures for remediation.
- We believe that children must be prevented from destructive acts against themselves, against others, or against property. Our first step in preventing destructive or disruptive acts is not to ask why children do what they do, but rather to take direct common sense physical action to prevent the undesirable behavior from continuing and then to try to determine the cause for that behavior.
- We believe that learning for the handicapped is not always pleasant for either the child or the teacher; however, we do feel that the pleasure that results from overcoming or circumventing a handicap is worth the transitory distress that may accompany the learning process. Our approach is to say, with grim cheerfulness, “It’s tough; do it.”
- We believe that children with neurological handicaps are capable of a great deal more work and accomplishment than most people have expected from them; accordingly, we have an extended, busy, purposeful school schedule.
- We believe that autistic children when isolated cannot help one another, but that a mixture of autistic and brain-damaged children is a beneficial combination, economically and educationally sound.
- We believe that education and socialization are not enough. We can and must train our children to do productive work, if they are not destined for normal academics.
- We believe that reward for good behavior is not a substitute for clearly expressed disapproval of unacceptable behavior.
- We believe that the families of our children can and must play a positive role in their education; that when autistic or neurologically impaired individuals reach late adolescence or early adulthood, they, like their unhindered peers, should leave home and live with their contemporaries in a homelike setting structured to allow a life as nearly normal as the individuals’ handicaps will allow. This leave-taking should be viewed positively, as a triumph over adversity rather than as capitulation to overwhelming misfortune, and should take place while the individuals and their families are young enough to enjoy its benefits.
- We believe that education should continue into adulthood so that individuals are not locked into the educational or vocational level they have attained at the end of their childhood years. They should have the opportunity to reach their potential at whatever age it can be attained.

Northside is the residential unit of Benhaven. Benhaven owns a 35-acre farm which straddles two adjoining towns, East Haven and North Haven. On the North Haven side, which we call Northside, is located a beautiful 11-room ranch house with a swimming pool. On the East Haven side of the property, or Eastside, is a more typical farm with a rundown farmhouse, two rundown barns, and a brand new commercial greenhouse, which our children use in their horticulture work. Our residential unit is a one-story brick house, which contains on the ground floor a living room, a kitchen, a dining room, four bedrooms and two baths. Two of the bedrooms are for staff, and two are for students. We also have in one of the student’s bedrooms a bunk bed for visitors. In that way our daily children can come for a respite. The basement of the house contains another complete carpeted kitchen; a bathroom; a laundry room; a garage; an L-shaped recreation room; and, in what was formerly a bomb shelter, a cold storage room.

When the residence opened in 1973, the main concern was that the way of life not be one of custodial living, but that there be a definite program for the residents and that the program be dedicated to the idea that the children must learn structured living as a complement to the structured learning they encounter in school. We started with the idea that a fresh staff should greet the children when they come home from school at 4:45 p.m. every day and that the evening hours until bedtime at 10 p.m. should be defined into periods, though the children should not be made aware of the periods as they are in school by the ringing of bells. We specified times for recreation, for doing the chores, and for relaxation.

Students coming home to Northside have one-half hour of the day of free time to do whatever they want, whether it be listening to records or pacing. After that, depending on the day of the week, they do their laundry, clean their rooms, help prepare dinner, help serve and clean up after dinner, or do work around the house such as taking
care of the chickens or doing ground maintenance. After dinner there are additional chores before the part of the evening devoted to recreation. At that point the recreation is geared to each child's needs. If a child cannot be involved in one activity because of a handicap, we structure an activity in which he or she can participate. The things that our children enjoy most are taking walks, swimming, going for a ride, shopping, and occasionally going to some kind of performance.

Just as in our school, we have short-term residential goals set up every month based on a task analysis of all the activities to be mastered. There are goals for learning to shave, learning good table manners, and so forth. Along with the school reports, we prepare residence reports, giving information on which activities and goals have been attained and which ones have not. If a child needs work, in a particular area, the residence staff informs the teaching staff; and together they work out procedures to enable the child to work on his or her weaknesses.

Two male house parents carry out our residence program. We have four students who are over sixteen years of age. In addition to the two house parents who live permanently at the house, there are approximately ten staff people who come from school and work through the evening hours to help until the children go to bed. When we started with four children, we needed four staff members because the children were so dependent and so difficult to handle that it was necessary to maintain a one-to-one relationship at all times. But now two are enough. We never allow fewer than two, of course, because of the possibility of sickness or accident. The good part of having staff persons who also work at the school is that they are able to observe the total relationship between the learning at school and the children's needs in daily living.

Parent involvement is sought and welcomed at our residence. We like the courtesy of a phone call before a visit to ensure that the student is home and the visit would not be interrupting an activity, such as a visit to the dentist that could not be postponed. Parents may telephone their children or staff members whenever the need arises. We have never found parents to be unreasonable in the amount of contact they made, so we have never limited visits or calls; however, should we feel that a student was unnecessarily upset, inconvenienced, or harmed in any way by too much parenting, we would not hesitate to discuss the matter with the family.

Some of our students go home every Sunday; some go home for the day every three or four weeks; sometimes they go home for a weekend; sometimes the parents come to Northside for dinner and a few hours instead. Frequently, parents of our students will invite all the resident students as well as the staff for a day or a weekend. Our students have many visitors. School staff members enjoy having dinner at the residence, dropping in to help celebrate holidays or birthdays, and having the students as dinner guests in their homes. In a way the residence, which never closes, is a focal center for all Benhaven after-school activities.

The costs of such a residential program are very high because of the amount of staff necessary; however, in comparison with the cost of custodial care, at least in Connecticut and New York, it is much more economical to spend the money for a place like ours. For example, at the present time custodial care for an individual at the Connecticut State Mental Hospital is $25,000 per year. This is with absolutely no attempt to make the residents self-supporting or independent in any way. That is, it costs Connecticut between $14,000 and $15,000 per year to keep a child in the local residence for the mentally retarded, such as the Regional Center for the Retarded. This does not include the cost of educating that child. Our costs for the upcoming year are $14,000 per child for the day program and $28,000 for the residential program. Connecticut's advanced laws provide that the towns and state combine to pay all costs. The state is, of course, very much interested in having Benhaven enlarge its residence to remove from the hospitals those children who can benefit from education as opposed to custodial care.

There is no cheaper way to provide services adequate to the needs of these individuals, and those in public office are the first to recognize that fact. To do so more cheaply would require a reduction in the staff ratio which is the key to success in this program. At Benhaven the staff ratio is one and a half teachers to one child. The residential unit operates on 365 days per year, and there must be back up staff at all times so that the regular staff can have two days off per week, a month's vacation, two weeks for sick leave, and four personal days.

Benhaven's experience with deaf or blind children obviously is not total. We have never had a deaf-blind child. We have had a totally blind child, two legally blind children, one totally deaf child, and one child who was severely hearing impaired initially but is now totally deaf. Our totally blind
child was a six-year-old boy who had behavior problems. He was mute and had not learned anything much by the time he was six. Our program was geared to preparing him for using braille when he got older. And this started as all our work in language starts, on the gross-motor level.

To get him used to the idea that his hand would have to give him information, we started with tracing with his whole hand a very thick cable-sized rope which was taped to the floor. After the rope on the floor, he traced a clothesline taped to the floor, then clothesline taped to a board and hung on the wall. Eventually, he was able to move around the room by following the rope. Our goal was to reduce this to string, and then to place knots in the string until, finally, we would use only the knots.

We were also very concerned that Donald be able to move around the building independently as soon as possible. This presented a great challenge because our building is a four-story building with inside steps and outside steps. And so after contacting the Department of Education of the Blind, we started on a program to teach Donald to use a cane. It was the practice at that time not to start children at such an early age, but we saw no reason not to. We had a man come and show us how a cane should be used, and then we taught Donald to move independently around the building.

During his two-year stay he improved significantly; however, he required operations on the shunt from the brain, and every time this operation was performed on him not only did he lose what he had learned but he also fell even further behind. We reluctantly concluded that he could benefit only from physical therapy. Although physical therapy is part of our total program, we felt he should go where physical therapy alone would be offered to him. We have two legally blind students in our school now. Both were expelled from their schools. Elaine was expelled from the school for the blind because she was so aggressive that the school could not cope with her any more. David was also placed with us because he could not adjust to his school. In Elaine’s case, an interesting series of events took place. Because she was already reading braille, staff members felt obliged to learn braille. I can remember the misery of that summer when I spent one hour per day learning braille. I wanted to be able to use it by touch alone, but I found it took one-half hour just to wake up the sensation in my fingertips.

During an evaluation of Elaine, our physical education teacher found something interesting. To determine the developmental level of a child’s grasp, he uses several tests. In some cases he simply hands a broomstick to the child to see whether the child’s thumb opposes the fingers or just lies on top of the handle. Sometimes he touches his third finger or his fourth or his little finger with his thumb. Then he asks the student to imitate him. When Mr. Davis touched his thumb to his third finger and asked Elaine, “Do this,” Elaine did it. We had not realized that she had enough sight to discriminate. At that point Mr. Davis touched his thumb to his fourth finger, and Elaine imitated that.

When Elaine came to us a few months later, the braille material preceded her, but I ordered that it be placed in the basement. Instead of using the braille, we set her down at the chalkboard and wrote an eight-inch high, lower-case b. Elaine had speech, but it was rambling, irrelevant, and compulsive. We taught her phonetically, and Elaine, with her nose almost pressed to the chalkboard, was readily able to identify the letters and make the sounds. We then reduced the size of the letters, and within two months we had Elaine reading with her face about two inches away from the paper. The only trouble with Elaine occurred when the teacher brought up the braille to see what Elaine could remember. When Elaine was confronted with the braille, she had a temper tantrum. Since that time, we have not worked on the braille. We made contact with a doctor who fitted Elaine with a telescopic lens, which she wears around her neck. This magnifies the letters so that now Elaine can read from a distance of eight to twelve inches, and she has started taking piano and recorder lessons. She typewrites and sews on the sewing machine.

David, the other legally blind student, had never learned any kind of reading. His language, too, was very repetitious and irrelevant. We have worked with him on changing his behavior, teaching him self-care skills, and teaching him to read and write. Now he is very happily and busily involved in vocational training. In both these cases there was enough sight so that moving around the building was not a problem.

We had one young man, Meyer, who was on a higher developmental level. He could talk, but did not understand other people. One of his fears was of physical contact with another person. An expression that we frequently heard from Meyer was “Don’t touch me.” We wanted to help both Meyer and Donald, the totally blind boy, at the
same time. We took Meyer aside and told him what Donald's problem was. We blindfolded him so that he could understand what life was like for Donald. We then told him that Donald needed help getting from the car that brought him to the school, and we asked Meyer if he would be willing to help Donald. That help consisted of leading Donald by the hand and take Donald's hand and lead him up the path to the school. He willingly touched Donald.

In terms of Benhaven's experience with deaf children, we have had one who was totally deaf before he arrived, another who was moderately hearing impaired and then became totally deaf during his years at the school. Totally deaf, Lee was being expelled from his school because of his severe behavioral problems. He was so hyperactive and so resistant to learning that he had not been taught anything. Until that point, we had never had a totally deaf child. Through the past four or five years, we have been able to reduce the severity of Lee's behavior problems and help him to learn. Now he is working on a fifth grade level, and we hope to be able to return him to the school for the deaf at some point.

Lee's entrance in our school resulted in a significant step in the history of education of the autistic. Because we saw as Lee's goal the return to the population of the deaf and, therefore, his need to use American Sign Language, we had to make sure that the staff who dealt with him was able to use and teach American Sign Language. Our speech therapist who had training in the education of the deaf made sure that those of us who taught Lee learned sign language. A large portion of our school population was not deaf but had not learned to communicate through any traditional channels. Our speech therapist had been successful in using sign language in working with the severely mentally retarded. It occurred to our speech teacher to try sign language with our autistic children who were not learning to communicate through normal methods. She took a child to a small room, put a blue block in her hand with the written word blue next to it, and said, “This color is blue.” When she said it, she made the sign for “blue.” She then replaced the blue block with a yellow one. She did the same thing with the yellow. The child this time was able to understand the concept through the sign, and in ten minutes he could sign the names of colors, and in two weeks was making two-word combinations. We then introduced signing to other children. At this point we have 18 children who have learned to communicate since we added sign language to our program.

Whether working with the deaf-blind or the autistic, one must stress the importance of starting communication skills as early as possible. For those who are going to have to rely on senses other than the normal ones, the use of physical therapy is extremely important. If children must understand directionality, laterality, and space, they must first become aware of their own bodies and the relationship of the world to their own bodies. A full-time physical therapist on our staff uses proprioceptive facilitation techniques, which are 100 percent effective in teaching the children the uses and limitations of their bodies.

At the same time and for the same purpose, we are working in the areas of academics and perception to improve the children's memory, particularly their sequential memory, space perception, and counting. Counting will be very important in terms of getting a young person through a building, for example. Deaf-blind children who do not have some of the handicaps of autistic and brain-damaged children can actually do better; they can compensate for their basic defect with some of the other skills. For example, deaf-blind children may desire to participate; deaf-blind children may have a great deal to communicate; deaf-blind children's behavior would be much more predictable than that of autistic or brain-damaged children. Deaf-blind children can have a good sense of touch, which would facilitate their ability to learn.

Some of the same opportunities for work that we make available to Benhaven children could be made available to the deaf-blind. For example, we manufacture campaign and conference buttons. The process is mechanical. A deaf-blind child can put the parts together and use the machine, too, provided the button design is purely abstract or decorative and does not require a specific placement of wording. We also run a print shop. Although setting the type is out of the question for the deaf-blind, they could use the machine. Harvesting crops is work that many deaf-blind could carry out. Collecting eggs from the chicken roosts and packaging the eggs can be done using only the sense of touch. We often develop teams of workers, combining children with complementary strengths and weaknesses.

In conclusion, what can be learned from Benhaven's residential unit is that a structured, predictable setting can be very helpful for the deaf-blind. And with a staff that is sensitive to their
needs, there is no reason why they cannot live in a residential unit. Mixing children of various handicaps can be very beneficial. At Benhaven we have autistic and neurologically impaired children who are not necessarily poor relaters. We also have deaf children and blind children. Deaf-blind children could be combined with the retarded who would have the sociability and the language, but who do not discriminate among people and would, therefore, be quite willing to work with other handicapped individuals. The deaf-blind could function with the retarded for another reason, namely that the retarded can move about with the deaf-blind and be more helpful. The main lesson we have learned at Benhaven is that we can make living and working together a success for a population of multiply and severely handicapped by combining strengths of handicapped individuals and providing a predictable, therapeutic environment in which their weaknesses are recognized but their strengths maximized.

With this philosophy we have been so successful that we have not yet found the maximum level of achievement our students are capable of. The higher we set our goals, the higher are their accomplishments. What this demonstrates, of course, is that heretofore too little has been expected. There is much potential waiting to be tapped, much productivity, self-respect, and happiness waiting to be brought forth. The challenge has been issued to those who work with these handicapped individuals. Like us, at Benhaven, those who work with the deaf-blind have accepted the challenge; and like us, they can look forward to enjoying the rewards along with those whose lives they are changing.
One of the most important achievements of the past two decades has been the movement of the handicapped from institutions back to the community. This return has affected the mentally as well as the physically handicapped, including children, adults, and the aged. The aggregate totals more than one million people. The large institutions are being dismantled for reasons that are all too familiar now. They cannot serve the best interests of their residents. However, those institutional settings that harness highly specialized expertise to prepare residents with community survival skills must be distinguished from those warehouses intended to isolate people whom the community regards as “marginal.”

“Survival skills” is an apt phrase. It implies that socialization or normalization requires the individual to adjust to community codes and norms to achieve a level of integration or at least pseudo-integration. Courage and bravery are qualities required for success in the attempt to integrate. The highest virtue is “to pass.” To be employed and to have a family are essential ingredients in fulfilling one’s obligations to society. In return, society is prepared to provide a modest income supplement as well as services to maintain the handicapped person close to the subsistence level.

This process is inherently one-sided because the model upon which it is based is as antiquated as the total institution. Communities need their handicapped people to become true communities. Community support systems need handicapped as well as deviant people in their midst to reach fruition, to maintain stability, and to serve the needs of the so-called normal population. The well-being of handicapped people is intimately bound up with the vague and abstract notion of community. Most communities need to change to become support systems. The absence of support systems is a reflection of the absence of community, a condition that affects everyone.

Early care for the permanently disabled or handicapped can and must focus on the goal of full emotional development for maximum expression of individual personality and temperament. We do not want to develop a standardized support system to which handicapped people are molded, but rather a flexible system which extends or withdraws support on demand. The best early training for youngsters develops the emotional maturity necessary for making the decision to frame demands on a support system, to rely on external help, or to rely on independent effort when each is appropriate. Community support systems require that their handicapped members make demands both for and against help.

What are the requirements of a good support system for handicapped community members? The model of disaster relief would not be sufficient for the lifelong needs of the handicapped. A structure which mobilizes community members for short bursts of extraordinary help is less valuable than a modest but permanent endeavor. A stable support system integrates the handicapped within stable and enduring community institutions. Parents and relatives play an important part in the support system, but their efforts are supplemented by those of neighbors, ministers, doctors, police, and shopkeepers. The integration is formalized and solidified by a contract for a support network. The contract is based on a “support profile,” which indicates the handicapped person’s requirements and his or her relationship to other members of the network.

At the opposite extreme to this human support model is the familiar model of sheltered care. Sheltered care professionalizes the provision of services to an extreme degree, segregating handicapped persons into communities under the guise of protection. In this framework the handicapped live in sheltered facilities, are employed in sheltered workshops, recreate in sheltered facilities.
and lose contact with the community. The professional helpers may be well trained and well intentioned, but their involvement is not permanent, and they are generally not fully integrated residents of the community.

The human support system is invisible. It requires few, if any, formal facilities. It does not segregate its clients and members from one another. It employs a minimum of professional helpers. It does not use large numbers of volunteers who are identified as such. Instead, it calls upon participants in the support network to fulfill their contractual agreement to carry on their normal function modified only slightly to fulfill the needs of the handicapped.

I have been associated with a support system for the mentally handicapped people in my own community. Its model of service provision fulfills many of the characteristics of an ideal system of human support. The model would require some revision to apply to the specialized needs of those with other handicaps and disabilities, but the over-riding structure would probably remain intact. Founded by the father of a mentally handicapped son, the Association for the Advancement of the Mentally Handicapped (AAMH), which oversees the community support system, is now entering its third year of existence. Information about this organization has spread widely in New Jersey, and new chapters are now being developed in several counties. The model is not perfect, nor is it the only suitable one to serve the needs of the handicapped. It is worth describing because it is innovative, community-based, economical, and responsive to client needs and community welfare.

The cornerstone of the AAMH program is the contractual agreement and support profile for the handicapped member. The profile specifies the details of the handicap or handicaps. It specifies the members of the handicapped person’s support system for both normal support and crisis intervention. It also contains details about medical and drug needs, personality and behavioral characteristics, family history, education, and vocational interests. The support profile becomes a contract and a network through the efforts of a support coordinator. The coordinator is a trained professional with expertise in working with mentally handicapped adults. In the case of prospective members who are finishing their work at training schools, the coordinator will help supervise the transition and the acquisition of community survival skills prior to the move into the community. In the case of handicapped persons who are living with a family, in group homes, or independently, the early service stage brings the member into a wider social network for integration into the wider community. The coordinator attempts to assist members who wish to live independently or in shared apartments or houses to be able to do so. For those members who prefer to be employed, the coordinator secures jobs or surrogate jobs that are consistent with work skills and specific handicaps. The support coordinator helps to arrange the housing, the job, and transportation. Fellow employees and neighbors, then, become part of the support network, too.

The support profile form is a public document shared in its different versions with all participants in the support network. It alerts the food market manager to the specialized needs of handicapped customers. In his or her contract, the manager agrees to devote a few minutes extra to assisting handicapped customers purchase food. The bank manager agrees to flag the accounts of mentally handicapped depositors so that the support coordinator can be alerted when unusual withdrawals are requested. The clothing store manager assists handicapped customers in their selection of clothing. The minister, the doctor, and the dentist are all drawn into this network of service provision. The homemaker is contracted, too, not simply as an undifferentiated volunteer. He or she is asked to invite handicapped people for Sunday morning breakfast with his or her family and for Sunday afternoon family recreational activities. Community members of the support network carry on their everyday functions but extend themselves to provide the additional assistance necessary to serve the needs of handicapped community members.

Often these informal helpers must learn how to help. The necessary instruction is the job of the support coordinator. Such instruction is implied by the terms “socialization,” “normalization,” and “humanization.” These notions apply primarily to the whole community rather than to the individual. The community is humanized, socialized, and normalized in the diversity of its resources and needs. The library, the gym at the YMCA; and the community swimming pool all become part of the support framework. The adult school, holding classes on cooking and community survival skills, includes handicapped students.

This service model emphasizes the skills of the support coordinator. His or her efforts are concentrated on the initial preparation of the support profile, the formation of the support network, and the effort at community integration, including
The coordinator's efforts on behalf of members are concentrated at this early stage and are then reduced to a standby status as the network becomes self-sustaining. The coordinator is available to intervene in crises and to evaluate members' progress. The experience of AAMH suggests that mentally handicapped people who are employed and living independently require one support coordinator for about 15 to 20 members. The ratio could be higher or lower, depending upon the severity of the handicaps and the commitment of the support network. The coordinator does not start with a fixed number of members. Instead, members are added gradually so that new members can receive a greater amount of attention.

This type of support system requires no direct service personnel other than the support coordinator. If membership fees are feasible, administrative expenses can be sustained internally. No other specialized facilities are needed in this system. The coordinator spends all the working day in outreach activities serving as a multiplier of human support service and as a community developer.

Mentally handicapped people are widely distributed in American communities and are represented among all social classes, all ethnic and racial groups. In every fairly large community, a human support system like that of the AAMH can find a sufficient number of potential members to develop its service system. Alternatively, one support system can serve groups with different types of handicaps, including the adult and elderly physically handicapped. The argument for specialization is based on the assumption that expertise about the specific handicap is a prerequisite for establishing a support network. Whether the support framework could function satisfactorily in very poor urban core areas, in sparsely settled rural places, or even amid suburban sprawl is questionable. However, the process can work in towns where there are shops, schools, banks, police stations, and churches; where pedestrians and police on foot, taxis and buses still exist; and where residents have at least some commitment to one another as community members.

The support coordinator can function best when children are prepared early for community involvement. Although these preparations will be described in a hierarchical framework, all the efforts can proceed simultaneously. The first stage is the personal support system, which is parallel to that of the normal child. If acquired in the course of growing up, personal maintenance, personal grooming, communication skills, an appropriate educational level, and vocational skills yield a more rapid and more comprehensive integration level. During their children's childhood and adolescence, parents must learn to ask for and to expect help in education, special services, counseling, legal aid, and public assistance for themselves and their children.

Handicapped children need competent parents. Parents prove their competence by making demands on their communities. Parents need to form a power group. If the numbers of deaf-blind children in a community are few, as will generally be the case, a group can be assembled by including parents of not only deaf-blind children but also other physically handicapped children until the numbers are sufficient. Service programs always have a political base. Parents should join the political game. They are entitled to receive help and to use their community. The communities will benefit by learning how to solve difficult problems. Parents should create "motion" at all levels with their children, schools, community services, and state and federal agencies. Parents should start their own newsletter to pass on news about successes and failures to one another at a parent's level. These preparatory efforts will reap important rewards when the children reach adulthood.

The key element in a possible community support system for deaf-blind adults is flexibility and the simultaneous consideration of alternatives so that the maximum number may fit somewhere in community programs and few will require institutional care. Plans and strategies are needed for at least the following functions: housing, employment, social networks, medical care, and financial management. The functions can be planned and integrated by a support coordinator. Comprehensive integration of these functions is important.

Organizers should strive for housing options that offer a maximum therapeutic level, not merely a barrier-free standard. They should not fix their minds on a group home model when a shared or individual apartment is feasible. Builders of multi-family dwelling units in the communities should be asked to provide and equip some of their units for handicapped people. Apartment neighbors can be brought into the support network. Houses should have interaction space, and apartments should be
easy to clean and well equipped. Large manufacturers, such as General Electric and Hotpoint, can be approached about special needs.

Employment or the job surrogate can be approached in two major ways: by training a person to fill an existing job or by creating a job to match the person. In five years much can be done to accomplish the latter alternative in both the private sector and government. Sheltered work is not the same as a sheltered workshop.

The social network must outlive the age span of parents. Frequent intervention by the support coordinator may be necessary until dependence on parents is replaced by dependence on an adult social network. The responsibility of parents and professional agencies must give way to community support. The onus of support is on the community.

Will the support coordinator system work for deaf-blind adults? Is the model responsive to widely disparate degrees of disability, or is a new model needed when handicaps are as severe as total blindness and profound deafness? No one will know until persons with expertise in working with these disabilities and in community organizing have been trained. The role of the coordinator is an adult parallel role corresponding to the dedicated expert teacher of the young. A training program should be instituted to prepare a select group of persons for this important function. It is not too early to start even though many issues must still be resolved through discussion, experiment, and evaluation.

The statutory programs at federal, state, and local levels are important; and they will become more responsive and generous if parents remain active advocates. But the best way to avoid institutionalizing the handicapped and to ensure a responsible social contract that extends beyond the family is the community support system. By 1980 the first substantial group of deaf-blind individuals to benefit from the recently expanded training programs will reach the age of eighteen. Parents must prepare for this time, and communities must be ready for these handicapped adults.
III. TRAINING THE DEAF-BLIND

The Treatment of Severely Disturbed Children with Sensory Handicaps

Marianne Frostig, Director
Marianne Frostig Center of Educational Therapy

In the course of many years, fellow therapist David Horne and I have worked at the Frostig Center with blind as well as sighted emotionally disturbed children who had been diagnosed as psychotic, most of them as autistic. Their treatment is the subject of this report.

Nothing seems to be more personal, more private, more difficult to convey than the feelings of those involved in helping disturbed children. This is certainly true of parents and to a lesser degree of therapists and teachers. Nevertheless, what the parents and teachers experience in bringing up children must be understood in the context of the social conditions of the time. This is a time of contradictions and confusion. Americans want to stop misusing and exhausting natural resources but also want to increase consumption to accelerate the economy. People are often not even aware that these two objectives are contradictory. Great numbers of youth are idealistic and seek new fulfillment and meaning by devoting their lives to the service of others. They are willing to live in austere conditions to achieve their purpose, while at the same time the crime rate among young people and even children has reached an unsurpassed high. Society advocates traditional work ethics, but nearly 10 percent of the population cannot find work. Society tolerates or even advocates continuing automation, which adds to the numbers of the unemployed. Such contradictions between proclaimed mores and everyday behavior concern parents and teachers because the children need to be treated with constant honesty and compassion and understanding—not only by those close to them, but also by society as a whole.

Contradictions also characterize education. Some educators emphasize the freedom to learn and the dignity of the child, advocating the promotion of human relationships in the classroom and the teacher’s understanding, love, and compassion. Other educators exercise a more impersonal discipline, emphasizing circumscribed skill learning.

The cleavage of opinions is also evident in the treatment proposed for children with severe emotional disturbances, whether or not they have handicaps. One camp of therapists—including Des Lauriers, Anthony, and us at the Frostig Center—emphasizes a fusion of educational and therapeutic techniques in the treatment of children with severe emotional disturbances. Such techniques strive for the simultaneous cognitive, emotional, and social development of the child. Basic to this type of education is the conviction that the principal element in the disorders of many severely disturbed and handicapped children may be defined in Pribram’s (1971) terms as a lack of readiness to respond meaningfully to input. The processing of the input—or, in a more familiar language, the child’s perception of the world, including himself or herself—is defective.

In this treatment approach, the supportive relationship with a teacher-therapist is a major tool in achieving the goal of enabling the child to perceive the world, to enjoy it, and to interact with it. The therapist guides the child from one experience to another, never pushing or demanding, always intent on diminishing the anxiety of the child.

In contrast to this global, multifaceted approach are methods of behavior modification which are more concerned with a linear progression, promoting small changes in the child’s behavior step by step. Hewett (1964), Lovaas (1976), and others have worked with this approach.

Although certain other techniques of operant conditioning differ from the approach discussed here, they are not necessarily in conflict with it. However, it is essential that this approach be used appropriately, not as the sole therapeutic method. Emotionally disturbed children with sensory handicaps suffer from a range of symptoms with various degrees of severity. A positive approach, including kindness, prolonged body contact, and the demonstration of the therapist’s understanding of the child’s feelings, is better than
the use of punishment or extraneous reward to cause children to focus their attention on the therapist or a specific stimulus. In this approach speech or action results mainly from the relationship with the therapist, the pleasing tasks presented to the child, or the therapist's ability to provide opportunities for the child to achieve mastery over an aspect of the environment and feel successful in the real world.

Aversive conditioning, in contrast to positive operant conditioning, seems to be justifiable very rarely, if at all. It should be used only in response to the most extreme pathology and as a last recourse. It could probably be considered appropriate only for older children who have been in a state of withdrawal for many years and only in situations in which mechanical responses are regarded as better than none at all or in which the life of the child may be endangered by his or her behavior.

Those measures which account for all aspects of development of the child should always be preferred to those which elicit a set form of responses and limited changes in behavior. Even though a child's principal disturbance may be a lack of readiness to respond to stimuli appropriately, treatment will affect all aspects of personality development: motor activity, perception, intellectual functions, language, and the social and emotional relationship to the environment.

In a research program conducted at the Frostig Center some years ago with 30 severely disturbed children, many of whom had symptoms of autism and about half of whom were blind, we continuously evaluated and classified each child's behavior according to deficiencies in six major categories: (1) motor activity; (2) perception; (3) language; (4) thought processes; (5) affectivity; and (6) social development. We also classified the therapist's responses under the same six headings with subcategories denoting the therapist's specific intent.

For instance, under "language" was the category "to promote speech by questioning"; under "affectivity" was "to uncover fantasies and to help in symbolic and direct expression." In addition, we counted the total number of responses that the child made in each session, the number of non-pathological responses, the number of running words used, and the number of different words used. A comparison from month to month of these figures can give a general idea of a child's progress, or lack of it.

We believe that the pathology of all children can be understood in terms of their developmental disturbances, whether they be diagnosed as mini-

mally brain-damaged, emotionally disturbed, or even autistic. We agree with Switzer (1963), who states that autistic children can be understood as suffering from global learning disturbances, involving every facet of development. Autistic children are at one end of a continuum which ranges from specific learning difficulties to severe general involvement. In the course of any child's treatment, every developmental area has to be taken into account.

Regarding the children in our study, we could observe that treatment proceeded in three stages which merged into each other instead of appearing as distinct phases. In the early stages of treatment, the therapist focused attention on forming as deep a relationship as possible with the child; in the second stage the therapist focused on the child's awareness of himself or herself as an acting and interacting being; in the final stage the therapist emphasized an educational approach to help develop the child's motor abilities, perception, language, intellectual functioning, and emotional and social growth. The child was thus helped to gain mastery over his or her environment in every possible way.

In the first phase, in which the establishment of a relationship with the therapist was the main task, success depended greatly on the therapist's ability to empathize with the child. The aim was to foster the growth of the basic trust or primary love that the child had failed to develop previously. The initial approaches included lap-holding, rocking, carrying, or singing and talking gently to the child. The approaches also included physically restraining children who were uncontrolled, preventing them from harming themselves or the therapist and from breaking objects. A consistent attitude of caring does not preclude setting limits.

The second phase of therapy, during which the main goal was to make the children aware of themselves as feeling, acting, and interacting beings, involved such varied techniques as skin stimulation (as Waa [1955] suggests); encouraging games and physical activity; imitating the children's actions or feelings; showing them their reflection in a mirror; and verbalizing what they were doing or feeling. We chose to persuade the children to undertake simple perceptual motor tasks, which might at first be frustrating but which could be mastered with help and which would eventually provide essential experiences of success and accomplishment in grappling with reality.

The third phase of therapy, concerned with the relationship of the child to the environment, is the most directly educational. The main emphasis is
perceptual development, giving a child every conceivable preceptual experience that he or she can tolerate. Toys and materials are used to produce a feeling of mastery in the child. Perceptual experiences play a dominant role during the first two phases too, but in those phases the emphasis is more on helping the child to perceive the therapist and himself or herself.

It is necessary to stress, however, that perception is not the only developmental function considered. As perceptual abilities increase, thought processes are increasingly emphasized. Language receives particular attention. Physical activity of all kinds is encouraged, especially that which involves conquering space by climbing or swinging.

A subsequent study of 30 autistic children who were treated at the Frostig Center revealed the following long-term results: 16 of the children were able to go on to regular schools; seven were partially rehabilitated, able to attend special classes in regular schools; five showed improvement, but since the treatment was finally unsuccessful, they went on to institutions or to schools for mentally retarded children; and in two cases the eventual outcome is unknown, though the prognosis was poor.

Fourteen of the 30 children were blind, mostly born prematurely, the victims of retrolental fibroplasia. Of the blind children, six were fully rehabilitated, six partially rehabilitated, one was institutionalized, and the outcome of one child is unknown. We found no essential difference between blind and sighted children, although the figures suggest that the prognosis is more favorable for sighted children. This may have been due less to the blindness than to the prematurity of the children in this group, with its presumably greater incidence of brain damage.

We are delighted with the knowledge that four of these children-two sighted and two blind-are proceeding satisfactorily in college, and one of these, the blind little girl shown in our film, The World Outside, has been graduated and will become a public school teacher.

The conclusion we have drawn from our experiences over the years with these children and hundreds of others is that during rehabilitation a fusion of those techniques generally termed therapeutic and those generally termed educational is of optimum benefit. In treating severely emotionally disturbed children, the steadfast satisfaction of the child’s excessive emotional needs should be supplemented by carefully calculated educational techniques designed to reduce developmental lags and to give the child the experiences of success. Educational success will in turn lead to improved means of communicating with others and a greater desire to do so.

Individual or group counseling or psychotherapy should always be provided for the parents of severely disturbed children. A family with such a child will inevitably be subjected to stresses and confronted by problems which skilled counseling could help with.

References


The World Outside (Demonstrates the treatment of severely emotionally disturbed children with autistic characteristics)
The Thrill of Victory and the Agony of Defeat

Herb Haas
Remedial Physical Education Teacher
West Valley School

The thrill of victory and the agony of defeat—those are the possibilities faced by a teacher in the daily task of trying to teach children. Every child is different; the needs and potentials of each child differ from those of every other child. Needs are determined by the use of goals and objectives. Potentials are determined by the degree of impairment. Some children are more impaired than others and will therefore require different movement activities or adaptations of these activities. Understanding these needs and potentials will enable the teacher to increase the chance of victory in movement activities.

The development of a fetus is similar to the processes of growth and development in a child. One of the first occurrences is the multiplication of cells. As the cells multiply, the fetus grows from the inside out, developing a central nervous system, organs, bones and muscles, legs and arms, and a sensory system. Depending on the method of birth, the child comes either into a well-lighted room where the doctor gives a slap on the back or into a very soft, warm, cozy environment. Either way, the child comes out, without looking around, without hearing all the sounds.

With the deaf-blind child, there can be different degrees of impairment, different levels of functioning. One child may barely function. Another child, also classified as deaf-blind, may move around, identify objects and shapes, and hear somewhat.

As a physical education instructor concerned with movement and with function, I would like to share some of my experiences—my thrills of victory, the experiences that excited me when I first taught a kid who could do nothing. I will cover the cycles of growth in a child, develop some ideas about movement in children, and present what I have found in applying theories of growth.

The Senses and Growth

Ideally, a teacher should develop all the major senses—visual, auditory, and tactile. In motor learning the best way to learn is by imitation. A person sees an action and imitates it, hears a sound and repeats it. If the visual or auditory sense systems are impaired, then a person must use the third system, the tactile. Although the ideal is to combine all three senses, a teacher must also develop to the optimum the one available to the child.

Vision

If I want to assess a child’s vision, I can read an ophthalmologist’s report, but that will not tell me what a child sees. What I might want to do is my own visual assessment. The simplest one that I have found is a flashlight in a dark room. I shine the flashlight around on the ceiling to see if the child will track the light, or I shine the light at the child and move around the room.

There are degrees of blindness, and I need to know how much a child perceives. I have put mats, pads, and bolsters around the room randomly and turned out all the lights. Then I brought the kids inside and let them wander around the room. For some reason they seemed to miss all the things set out on the floor. They did not trip; they did not fall. Somehow they perceived what was around them.

To find out how much the child can really perceive, I use a rear-screen projection. I place a light behind a sheet with someone standing in front of the light. Placing the child in front of the screen, I would see if he or she could mimic the shadow. For example, the shadow would move its arms out to the side, and I would see whether the child saw the movement. The results were interesting. The children would go to the screen, place their hands about where the hands were, and follow the hands around. In other words, there was some visual stimulation. The smaller, younger children would see only things within the body line. They could perceive the hands close to the body, but they might not see the arms when extended fully. Older,
more mature children could perceive movement farther from the body; and they could perceive fine movements like turning the hand and closing the fist.

Teachers have to start thinking about their presentations to their students. They must realize that if a subject is presented without regard to the child's field of perception, the child may miss everything. They must understand what the child sees. They have to narrow their vision and see what the child perceives. With the child who has no sight, who cannot respond to any of this, a teacher has to go on to the next sensory area.

Hearing

As a physical education person, I know nothing about hearing aids except that they amplify sound at different levels; and if the child is not wearing one, he or she does not hear as well. I tested gross hearing skills, with a drum, talking, or just a noise. If the child turned, I knew he or she could hear. By playing with the loudness and the pitch of the drum, I could estimate how much the child could hear. This was just a gross way of testing whether a child hears. Next I tried placing the child differently in relation to the sound, both without hearing aids and with hearing aids using different amplification levels. I tried something called transducers, which are just large hearing aids. If I attach a transducer under a wooden table or piece of plywood, the wood becomes a vibrating surface or sound board. This does not make children hear any better they have nerve deafness. I seat the children on the sound board to see whether they will respond to the vibrations of the music. I use exciting music, music that makes a person want to move.

Touch

The third sensory area—the tactile, or kinesthetic—is another interesting area. What does a teacher do with a child who does not respond tactilely? The child who cannot see, hear, or feel is a challenge because everyone should respond to touching. I asked myself how many ways I could touch a child. By touching and using vibrators, I found, for example, that many children did not do anything. I thought about what other types of receptors are in the body. Since there are hot and cold receptors, I tried water: warm water, cold water; warm objects, hot objects. I found that sometimes this did not work and sometimes it did. Then I tried soft and hard objects without success.

Finally, I came upon it. In my days in college working on my master's thesis, I worked in the athletic training room. There sharp and dull objects were used to test for nerve injury. The sharp and dull test was the thing that worked on most of the kids. Even if I got nothing out of hot and cold or soft and hard, sharp and dull worked. I, of course, cleared this procedure with a doctor before using it. There are medical instruments for such nerve testing. They are like wheels of pins of varying sharpness. To check a nerve reaction, I run the little wheel up and down the arm.

I tried the test on one youngster who responded to nothing else. Hugging him and cuddling him had no effect. When his hand was put in warm water, he did not realize it was his hand. He gave no reaction at all. Carefully, I started with the dull points and found nothing. Then I tried the sharp. All of a sudden something belonged to him. He "discovered" his own hand! It was out there, and it was a part of him. Something had gone through his motor sensory pathway and said, "This is my hand, and it hurt." I had found the way to help Barry find his hand.

A teacher has to look for victory, in little steps. This was the first victory with this child. From what had been nothing, I got my gold medal, my reward. I found something that stimulated Barry. Barry was able to move on to other kinds of touch, but I cannot explain physiologically why he was able to go from dull and sharp to touch.

It is important to realize the body has these three systems, the visual, the auditory, and the tactile or kinesthetic. When something stimulates the system, an impulse travels up through the central nervous system: The brain interprets what has happened and tells a muscle to move. The three sensory systems are integrated, then, in the sequence of perception and reaction: from the sense; to the central nervous system, which interprets; to the motor muscle system, which responds.

The Idea of Movement

What happens might be a very small twitch. That tiny twitch might be the key to the whole system's analysis and function. If I wanted to lift a teacup and drink from it, I would use the muscle, the skeletal, and the visual systems. I would look at the teacup. I would pick it up, lift it to my mouth, and put it down. If I thought I had a very heavy lead mug to lift and I was going to do the same action, I would have to use more muscle. I would have to use more nerve endings firing into the muscle. The brain
then would have to interpret the heaviness and send the appropriate messages to the muscle. If I made a mistake, lifting the teacup with the same strength that I would use to lift the heavy lead mug, the cup would go right over my head. I would have had a misinterpretation going into the brain; I would have to readjust. Since circumstances change with each type of motor activity, teachers have to ask constantly what a child responds to, what does he or she see, feel, and hear. Teachers need as much information as they can obtain.

As teachers we try to help children perceive. In doing this we have to be genuine. We have to understand what the child feels. Everyone has gone into a classroom when having a rotten day and been unable to pay attention even though the professor was giving an exciting lecture. Some teachers are hard to listen to under any circumstances. Others can excite the most lethargic students. We have to do that with our students, too. They have to feel wanted. They need a positive response to whatever they do. In trying to stimulate the sensory organs, we have to feel what the child feels. If he or she had a bad night and does not feel good, all the things we try are not going to help. We have to size up the child each time we try to work with him or her.

In our motor program, as we look at growth and development, we also have to look at the individual. We have to say that Jimmy is in a fine mood today and he is going to learn a great deal. If Jimmy is blase, we have to let Jimmy sleep sometimes. We cannot impose on him.

Getting a Child to Respond

What would be the best way to present a stimulus, a ball, for example, to a deaf-blind child? The answer is touch. As I said in my theory of growth and development, I do not want to present it from the side; I want to present it down the center. I do not want to present it as a threat, but as something that will be comfortable and warm. I have to present it to a child in the center. Children responding normally are going to grasp it. Functioning in any way, they are going to respond somehow. They might turn it, hold it, but they will do something with it. If they are lying on their backs, I might pass it over the head or down by the center of vision so that I can put it on the stomach, and they might respond or move to it. If they do not respond, I have to present it in a different way.

The ball should be presented slowly, giving the children a chance to feel it. A large ball is best. The children must sense the ball, feel it, know that it is there, know that it is soft. The teacher could also pull the plug on the ball. The shrinking ball is going to provide a new tactile sensation. To advanced children who can sit up, I might present the ball in a straightforward, manner. I might start them reaching for the ball and catching. They can reach and feel the ball, and they can feel what is happening with it. They do not know yet that they are going to roll it back to me. With one child I found that when she got tired of exploring and turning the ball and I tapped her, she would give me the ball. But I had to watch to see when the child was getting frustrated with it. Teachers must take their cues from the child. Teachers have to try all the means possible to communicate: talk, signal, touch.

Suppose as the next step that we want the children to play on their own. We can hang a ball. If it is a bright ball, they might see it and push it around and play with it. If it hits them, it is going to hit softly unless they get violent with it.

Theories in Physical Education

The first theory I would like to talk about is the S.A.I.D. Theory. S.A.I.D. stands for Specific Adaptations to Imposed Demands. This means that if I want to teach children to catch a ball, I have to give them a ball to catch. I cannot lecture on ball catching; I cannot show a movie on ball catching. I have to let the children catch a ball so that they can experience ball catching. If I want to teach children to swim, I have to put them in the water. I have to be in the water with them. I have to let them feel water, explore water, find out that they cannot breathe under water. The practice has to be specific. If I want to run the 100-yard dash in 9 seconds, I have to practice running the 100-yard dash in 9 seconds. If I practice running it in 12 seconds, I am not going to run it in 9 seconds.

Practice. The idea of practice deserves more attention. If a person is going to practice a skill, that person should be allowed the opportunity to explore and learn. That a person does it wrong does not mean that he or she is incapable. It means that the biofeedback was incorrect. Children should be allowed to kick the ball. If they kick it wrong and the ball goes over there, then they will have to find it. The teacher should not put it back in front of them and say, "You did it right." The children should come to the ball, kick it, and find out what they did wrong. In early motor learning children should be allowed to practice and explore.
**Being positive.** In higher levels of competition, the teacher must be specific with correction, but positive all the time. A teacher should always be positive in motor learning, never giving a negative cue. For example, in teaching springboard diving to adults, the teacher should come on the springboard and say, “Go find the end of the board,” and let them walk to the end of the board. Then the teacher should say, “Take three steps backwards, turn around, and mark your step. Now you’re ready to do your dive. Take three steps, jump, and bounce. One, two, jump—off you go. That’s great.” A teacher who tells them to start on the left foot will have interrupted the whole motor sequence that he or she wanted to teach.

What is told to children should be positive. If teaching soccer, one does not say, “Don’t pick up the ball.” One says, “Kick the ball.” The teacher should move a child’s hand out of the way so that he or she is not reaching down. When the child is using the foot, the teacher should offer compliments and encouragement: “Great, you kicked it.” Children need feedback. They want to hear, “That was good; you did the thing we want you to do, and that’s exciting.” Effective learning requires practice in a positive manner and practice with positive reinforcement.

**Fear.** Fear will negate all the things a teacher wants to accomplish. If a child is afraid to step onto this mat, it will be difficult to teach him or her. A teacher has to build trust; then a student will learn. If a teacher is positive and avoids introducing fear, the child will learn. But if fear enters any aspect, any type of activity, the child will not respond.

When children are given a tire to explore, they will usually go around it to feel what it is. Next they might crawl onto it or walk around it. They will probably explore the tire more readily in a down position because they cannot fall very far and, therefore, feel comfortable. Teachers might want to ‘give the children a thumb to hold to help them stand. If children are afraid, they are going to hold on tighter, letting the teacher know of the fear. If the teacher can calm such children and hold the other hand, then they might not be afraid. The sensor is going to be the squeezing of the thumbs. This is true 99 percent of the time. If the children are comfortable, they are not going to squeeze too tightly. In extreme cases of fear, an odor emanates from a child. I have experienced it three times. Animals can sense it right away, but humans do not sense it until the highest level of fear is reached. It can be sensed earlier through the hands, the body, or the position. If the children are tight and inwardly drawn, they are afraid. They are not going to perform, or they have another physical handicap that the teacher has to be aware of. The thumb technique is the best means for monitoring how children feel. It also affords some control by making it easier to hold a child and protect him or her from falling.

Tension also inhibits performance. Tension is not necessarily fear, but a tightness that prevents movement and exploration. Movement releases tension. Movement allows relaxation and a feeling of freedom. A teacher must decide for each child whether he or she is comfortable or fearful or tense and find some way to ease the fears and tension. Stroking the back or the midline is probably one of the best things to do.

**Readiness.** Another important aspect of learning theory is readiness. Readiness means that the child is physically, emotionally, and mentally ready to perform a task. If a child’s bones and muscles are not developed enough to support the body’s weight, a father’s lifting the child and trying to show him or her how to walk will not improve the performance. As a matter of fact, it is probably going to hinder performance because the stress is going to curve the bones and distort the feet and gait. A parent may cause injury without being aware of the harm. A child has to be physically, emotionally ready to move. Children have to be mentally ready to move, too. If the children are not ready to perform an act, all the practice in the world will not mean anything. If children cannot crawl and move their arms in coordination with their legs, they are not going to be able to move their arms in synchronization. If children cannot catch a ball coming straight at them, they are not going to be able to catch one coming at them from the side. If children are not ready or if they miss a step in motor development, they need to go back and learn it before going on.

**Learning plateaus.** Another phenomenon involved in learning theory is what is called learning plateaus. Children may learn something and be excited about it and then not learn anything for awhile. They have reached a learning plateau. Growth is not just steady improvement; it levels off at times. The periods of leveling off do not mean that the teacher cannot teach. They simply mean that the student has reached a maximum for the time being. The teacher has to decide whether to go on to the next step and progress slowly or to stay on the present level and try a different activity. Variety in activity is important.
cannot do the same thing every day. They will become bored. If a program is not working, teachers should not "hang in" there. They should try something else to accomplish the same goal. They should be flexible. Children are flexible, but if they are not ready, no teaching or training is going to change them.

Motor Learning

I have covered theory, growth and development, and motor sequencing. Now comes motor learning in sequence training. As a teacher I must decide what objectives to aim for and what level to start on. I will begin with a very basic level. Suppose a child comes into the center and sits there and does nothing. First I would want to work on stimulating the child somewhat. I would use some of the things that I used before—the light, the sound board, the tactile stimulation—to get the child to react to me. I will try everything I have.

The other thing I will do is to compile a checklist as a tool for measuring the child. I will develop something to show me what the child does.

Stimulating the Child

For tactile stimulation in a classroom, I use a socio-bowl. It is made by Skill Development Equipment Company. It is expensive but worthwhile, a good tool for getting closer to the children. We all get in the bowl along with some balls and put the lid on. Then we start touching and feeling and becoming people, knowing that we are Barry and Judy and Joan and John and knowing that those around us are other people who touch and feel, too. Then we put different mediums in the bowl, like packing styrofoam to stimulate tactile responses. I observe how the children react to different media and to each other. When I get out of the bowl and leave them alone. Then we all climb in and put the lid on to get back to the "womb."

We use vibrators to touch different parts of our bodies. We find that we have belly buttons. Tickling is an excellent activity if it is used properly on kids who are ticklish and get excited about it. When they are tickled, they discover different parts of their bodies. Tickling can be fun if it is not overdone.

Textures. Popcorn, marbles, and sand are textures that are fun to explore. A sandbox is a valuable tool, but if one is not available, a little box can be used with large grains of sand in it and toys to play with. A box of popcorn or of seeds works well, too.

Another thing that I do is to place several boxes around the room and let the children crawl around barefoot from box to box. I put a piece of carpet on the floor and let the children crawl across it, or across a smooth floor, or a piece of wood, or a piece of astro turf. Carpet stores will often give away remnants for such uses. Pieces of chain-link, rope, net—anything that offers texture that the child can move through, explore, and feel—will be valuable classroom tools. If the children are not ambulatory, then bring the textures to them in a box. Let children at lower functioning levels touch and feel, especially sand and different things to play with in sand. Other possibilities include a beanbag chair, a waterbed, and a Port-a-Pit (an airflow mattress).

We also use shaving cream. We put it on our faces and "shave" with tongue depressors. The next step is to tell a male teacher not to shave for four days. After the children feel his face, we have him shave half his face. Then the children compare smooth and rough. Then he shaves off the rest and lets them feel again.

Headstanders. Occasionally we have headstanders, kids who stand on their heads for stimulation. Jean Ayres of the University of Southern California studied headstanding deaf-blind children and found that they wanted stimulation to the vestibular tubes in the inner ear. What is vestibular stimulation? Inside our ears we have canals that are filled with fluid and little hairs. As this fluid moves, it stimulates the hairs to indicate what position the body is in. That is vestibular stimulation. The child who does not move around much needs this stimulation. We found that spinning a child in a cargo net would eliminate headstanding completely within about two weeks. Instead of a fancy $200 cargo net, we bought a hammock, the cheap type for about $3.95 from a local sporting goods store. We would spin the child back and forth and up and down in the hammock through three dimensions. This activity also had a side benefit. We got visual tracking from the children who were waiting as they watched the spinning child. The children did not even become dizzy.

Falling and reaching. Another thing we wanted to do was to explore the falling and reaching aspects of balance. The normal reaching reflex protects children when they fall. To teach children protective extension, we put them in an upright position
and measure their ability to fall. We found that we could teach children to accommodate. By standing behind the children where they could not grasp us, we could teach them to balance and compensate for their movement. Using a thick mat, we could have the children fall forward from a standing position, protect, and extend. Next, we taught the children how to fall, roll, and tumble. Port-a-Pit equipment or Skill Development Equipment is invaluable, because with it anybody can teach gymnastics safely, without injury.

Teaching Numbers and Letters

We can teach the higher functioning child to identify numbers, letters, and shapes. We start with the basic shapes concept: circle, triangle, square, and rectangle. From those shapes children can then identify the letter/number concept. From letters and numbers children can go into reading and writing and other things. On the floor we painted letter grids, called Cratty Grids because they were developed by Briant Cratty at UCLA and discussed in his book Movement, Perception, and Thought (1969). These figures are 2 feet in diameter.

Sandpaper. On the board in front of the grids are pieces of sandpaper with the same shapes drawn on them with a felt pen. To arouse tactile stimulation, we draw a child's hand over the sandpaper shape and ask him or her to identify the shape on the ground. We have also used blocks to build the shape “square.” By adding one block, we make a rectangle; for a line, we just lay one block flat on the ground; for the circle, we use a sphere. Skill Development Equipment makes a rolling sphere that the child can get into. So the children identify all the shapes in a gross way, three-dimensionally, and then tactilely by using the sandpaper. We find which way a child can identify the shapes and build from there. Some children can trace the shapes by “walking” them. They can eventually walk the letters and numbers. This is not pencil and paper work; this is ground plane discrimination. “Walking” letters and numbers is the next step after gridding toward reading and writing skills. Gridding can be done out on the playground with lime, paint, or chalk.

Socio-bowls. We found that the innertubes from school bus tires cannot legally be used on buses once they are punctured. We arranged to have the punctured tubes repaired and sent to us. The innertube serves as a socio-bowl. The stern of the innertube should be aimed downward so that the children can bounce and roll around safely.

Measuring Progress

It is necessary to find a measuring tool or some way to evaluate students’ gross motor skill development. The Los Angeles Unified School District uses System Fore. Many commercial tests are not specific enough in their standards. The Terminal Performance Objectives motor sequence inventory developed by Los Angeles County schools is probably the best tool I have seen on the market. It was written as a group effort by people in the remedial physical education program, the psychology department, and special education. It would have to be adapted somewhat by changing the types of instruments used (like the ball), but it is a good basic foundation. I use it to make up a sheet on every kid in school. I can also relate the results directly to other results of the System Fore method.

Sequencing and Programming of Children

Sequencing and programming children can start with teaching a child how to roll over by pushing and feeling. I use the word “roll,” telling the child first to roll to the right, then to the left. I do not complicate directions. I say the thing and demonstrate it to the child. Then I let the child explore and do. To teach the child to roll, I lay the child down and roll the child. Some people say the arms have to be in to the sides; some people say the arms have to be over the head; I say let the children put their arms where they want to—they will roll!

The “tickle roll” is an excellent way to teach rolling. A person will turn away to avoid being tickled in a sensitive area. When I lay a kid down and tickle, the child rolls over and over down the mat as I keep tickling through the midsection. Another technique we use in teaching rolling is visual tracking. We lay a piece of tape across the mat, and the child rolls to the tape and visually swings over and finds the tape each time. We do not worry if children roll off to the side first. We just let them roll and explore, feeling the experience of rolling. There is no right or wrong way to roll.

We had a child who never crawled. The child would fold his legs under him and scoot, covering about 2 feet at a time. He could move anywhere on the floor, but he never crawled. Eventually, he walked. At four years of age, the kid learned how to shoot baskets with a regulation basketball. By the time he was five, he could hit a tennis ball back and forth with a regulation tennis racket; he could also pass and punt a football. His dad believed in
letting the kid practice on his own. He did not overteach. He avoided complicating the task. Children should be allowed to explore after being given simple commands to follow.

**Gross Motor Skills**

The training should start with the gross motor skills, those skills that involve moving the body someplace. Locomotor skills are crawling, rolling, walking, jumping, hopping, skipping, and galloping. They all follow each other in a sequence. Children cannot be expected to gallop if they cannot skip.

The incline mats are the best tools for teaching rolling and tumbling. Using the bolster, I can place children in a prone position and lay them over the bolster and look for the reaching reflex, protective extension. Then, I let the mat support the child. Placing the children on the mat and placing my hand on their backs, I let them roll forward. It is very important to protect the neck. Using the big Port-a-Pit mat with a bolster, I have an injury rate of almost zero. Using the mat system, I was able to teach deaf elementary school children to do running forward flips.

**Balance.** To teach balance, we use large things. We start with walking on lines, but lines are not the same as being elevated. So we also use telephone poles, because they can be cut with chain saws and stuck in the ground to form steps. They can be painted bright colors, too. We get the kids to come up, find the pole, put a foot on, and step up. They explore from there. They are forced to use their vision because if they do not, they fall.

**Ball catching.** Again, children should be allowed to play, to explore the ball. I start by having the children roll a beach ball or a balloon back and forth. It is best to use bright colored and shiny balls, because the kids are more attracted to them. A balloon suspended from a string or held on a stick can teach children visual tracking as well as give them pleasure. The next thing to do is to extend the visual tracking. Besides using their hands, the children can use bats, rackets, and other simple devices to extend eye-hand coordination.

The children may also try rolling balls down tubes (cores of carpet rolls work well) and dropping them in holes. These are manipulative tasks. Children may be asked to catch a ball when it comes out of the tube and put it in a container. A teacher must remember to reward children every time they do a task correctly. They should be told that they are doing a good job. If they do it incorrectly, they should not be scolded. Instead, the teacher should say, “Try again; try harder; do something else,” and pat the child on the back.

**Crawling.** The heavy cardboard tubes, that carpets are shipped and stored in make excellent tunnels for crawling practice. The “tunnels” are fun to crawl into and play with and can be included in an obstacle course. They can also be turned into slides by being leaned against a counter. Some children need stimulation to go through a tunnel. One of our children was stimulated by air. When we placed a fan at one end of the tunnel, John would crawl toward it. This was a tactile sensation. A light or a sound could also be used. Another way to start a reluctant child is to have another child push him or her through the tunnel. Once the children are in, the teacher can raise the tunnel so that they slide down through the tunnel.

**Creeping-crawling.** Other locomotor skills are involved in creeping-crawling. If children are not ambulatory, then a scooter board, something equipped with appliance wheels or casters, is helpful. A bigger board can be made with an old motorcycle tire by putting the tire around the board to form a protective edge. With the board children develop gross motor skills, upper body strength (by pulling with the arms), and lower body strength (by using the legs). We set up a course, using chairs, traffic cones, tables, and a miniature stoplight; and we taught traffic safety using the scooter boards as cars. When the children saw the green light, they had to go; on the yellow light, they slowed down; on the red light, they stopped. We had speed limits, a policeman who gave tickets, traffic fines, and a jail for speeders. The teachers had as much fun as the kids. We used light again, sound, and obstacles to go through and around. The children also had to clean up each time. In other words, they were involved in socialization, too.

**Speech development.** The physical education period is also a good time to work on speech and language development. When the physical education teacher teams with the speech therapist and the other teachers, the physical education period becomes fun for the children. It is a very rare child who does not enjoy the movement activities.

**Music.** I use Hap Palmer records and the sound board with our kids. The sound board is just a piece of plywood with a single transducer. Some people mount transducers in a series, but we found one does the same thing as three. The transducer is
Swimming is probably the best single movement activity.

Interaction Programs

It is exciting to involve handicapped children with other children and get them to interact. We had an interaction program for deaf-blind with the deaf, for deaf-blind with the totally mentally retarded, and for deaf-blind with nonhandicapped preschool children. We involved all the teachers and the paraprofessionals. We integrated the physical education program. We would go to a school for nonhandicapped students and participate in what they provided for us. Our children were expected to perform and work within their own group; therefore, we did not have the type of social interaction we were looking for, but we had acceptance.

We had only one negative experience: a nonhandicapped child did not understand the hearing aids and the glasses. At home he had nightmares about them. After that situation occurred, we began an inservice program with the teachers in which we explained to them what happened. As a result, we started to take the hearing aids and glasses to the nonhandicapped children so that they could explore the world of the handicapped. We let them look through glasses without glass in them and hear through the hearing aids turned down low. We found we had a better program because of it.

We give our children a choice in their education, too. They are not just put into a program; they have a choice within the program. For example, when we went to the preschool, if John wanted to go to coloring or to blocks or to puzzles, he had that choice. No choice was forced upon him.

Once a deaf child could not get out from inside a tire, so he turned to a hearing child and said, "Help me." The other child reached down and helped him out. That does not happen with the deaf-blind because they do not have language yet, only sign language. We taught some signs to the deaf-blind children, and they communicated with the deaf-blind. When we walk to the other school, we do not guide the deaf-blind children; we let the other children work with them.

The important thing to remember in this type of program is that children play in parallel. They do not always play together. Playing in parallel means that two children playing on the tires, for example, may both be playing on the tire, not with each other. They are playing "tire." That is normal growth and nothing to get upset about. Teachers must learn when not to teach.
Auditory Training for Deaf-Blind Children

Elizabeth W. Soper
Institute for the Study of Mental Retardation
and Related Disabilities
University of Michigan

The ultimate goal of most auditory training programs is to improve the hearing handicapped individual's communication skills—specifically, oral communication. The hope is that the children will learn to associate meaning with the sounds they hear and thus improve their understanding of spoken language and their own vocal output. The typical auditory training programs may incorporate a "natural" approach to exposing children to sound, especially speech, or they may emphasize systematic and somewhat contrived sequences of stimulus-response paradigms in order to develop auditory functioning. It has been demonstrated that auditory training programs can be successful with many deaf children, particularly those who have no other handicaps. However, these programs have not seemed as applicable to the multiply handicapped youngster. Whether these procedures, or even the basic goals of the auditory training programs, are either appropriate or realistic for the children classified as deaf-blind is questionable.

This is not to say that such goals should not be set for deaf-blind children or that traditional auditory training approaches should never be used with them. But the treatment of those children for whom the other methods are not applicable requires an alternative way of looking at auditory training.

Two primary points about deaf-blind children and auditory training will be addressed here; then they will be expanded and clarified. The first point is that those who work with deaf-blind children need to be aware of the severe emotional ramifications which may result from the reduced sensory stimulation that these children encounter. Secondly, auditory training programs for these children might consequently be based on developing an essential sensory contact with the outside world and be concerned with the emotionally reassuring aspects of hearing rather than the traditional learning-based aspects, which are more typically emphasized.

Many have written about the serious effects of sensory deprivation on human beings. Most of the experimental literature is derived from experiments on normally seeing and hearing adults who are put into situations that impose an absence of external stimulation artificially. The results of these experiments have been compared with the experiences of children who suffer defective sight and hearing from birth or soon after. Vision and hearing, which are termed the "distance" senses, allow one to maintain contact with the environment. For the other senses—taste, touch, and smell—the objects of perception must be much closer. Children without sight or hearing are severely cut off from their external environment much of the time. Studies show that people do not easily tolerate long periods of sensory isolation when the isolation is artificially produced in a laboratory. Researchers have concluded that people need a constant assurance from their environment in order to maintain their sense of well-being. Deaf-blind children live with sensory isolation from the moment of birth. The impact on them of this deprivation may be different from that on an individual who has past experience to compare with, but the impact is no less significant.

Vision and hearing are also the senses through which people typically reach the higher levels of perception and cognition. With the absence of one of these senses, an individual tends to depend more heavily on the other for all learning as well as for basic environmental contact. Deaf children are constantly scanning the environment visually. They are acutely aware of things that enter the periphery of their visual field, turning quickly to explore the objects. They often learn to communicate through vision, by lipreading, by sign language, or through the written word. The blind, on the other hand,
The psychologist's impression was that Brenda had a severe affective disorder manifested by self-stimulatory acts. The report said, in part:

Her behavior while she tried to complete some formboards was characteristic of the autistic child, are often observed in deaf-blind children from an early age. The typical self-stimulatory mannerisms and the apparent lack of interest in the outside world, which are characteristic of the autistic child, are often observed in the deaf-blind child.

Some of these patterns can be noted in Brenda, a post-rubella child who was diagnosed as deaf-blind from an early age. Brenda was six years old and had made minimal progress in school. Her teachers "felt somewhat at a loss as to what might be methods or techniques to get through to this child." One evaluator at the center described her at that time as follows:

As I was observing Brenda around the clinic with her mother, she frequently seemed to be in a world of her own. She responded to direct physical stimulation such as tickling. . . . Otherwise I observed her to initiate no activity. . . . She amuses herself by flipping things in front of her eyes and playing with brightly colored plastic toys.

Six years later Brenda was sent back by the same school for diagnosis with much the same referral questions. In six years Brenda had made some limited progress, but her teachers still experienced problems that centered around her relating and attending.

The psychologist who evaluated her described her behavior while she tried to complete some formboards. The report said, in part:

She appeared not to attend, not to notice, not to respond to the formboard or to the tester. She moved continually, bobbing her head, looking up toward the light, avoiding eye contact with the board, the forms, the tester. She fingered the forms and occasionally mouthed them. When given firm encouragement and signs for performing, she evolved a ritualistic schema, training the tester to go through a sequence of ritualistic acts to achieve her cooperation and performance.

The psychologist's impression was that Brenda had a severe affective disorder manifested by schizo-
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-ness. Fie tracked lights, pulled objects close to his
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children tend to use their remnants of vision to
much greater extent than they use their hearing. It
seems that children with limited vision consistently
tend to strain to utilize whatever visual input is
available. Just as consistently they tend to ignore,
or at least not take meaning from, the auditory
stimuli in the environment. An example of this
tendency is the behavior of two-year old Robert.
Robert was developmentally delayed, though not
severely so, and he had been previously diagnosed
as legally blind. He had light perception and
minimal ability to see large objects held close to his
face. He had been seen by a number of audiologists
for hearing testing beginning at the age of eight or
nine months. Reports of his hearing were very
inconsistent, ranging from "probable severe hearing
loss" to "probably no significant problem."
At first he had no language, no apparent
understanding of speech, no vocal imitation, and
minimal babbling. He would occasionally react to
loud sounds by starting, by ceasing his activity, or
by blinking; but he would never turn toward sound
nor search for sound in any way. By contrast he
was quite visually attentive in spite of his blind-
ness. He tracked lights, pulled objects close to his
face to examine them, and reached out for any
large objects which entered his visual field. Cooper-
ative and fairly bright for his age, Robert could be
conditioned by tangible reinforcement operant
conditioning audiometry (TROCA). Tests showed
that he actually had a moderate degree of hearing
loss, his thresholds averaging about 50 decibels. He
definitely had a hearing loss, but certainly he had
much more residual hearing than residual vision. A
hearing aid was immediately recommended and an
intensive auditory stimulation program was initi-
ated. Now, four years later, Robert uses speech
meaningfully and responds well to spoken language
and to other environmental sounds. He still makes
good use of his vision as well, although he has had
no intensive visual training.

Why did Robert have to be "taught" to use his
hearing when he spontaneously made the most of
his small remnants of vision. This pattern repeats
itself many times in children with hearing losses
ranging from moderate to profound and with
varying degrees of visual capacity. The discrepancy
in the use of the senses is puzzling and, as yet,
extremely immature and inappropriate. Unfortu-
nately, she had had very limited training opport-
unities. If she had used amplification from an
earlier age, she probably would have developed
much more appropriate contacts with the external
world and fewer maladaptive behaviors.

Children who have limited vision and hearing
often seem to use their residual senses quite
differently. Michelle's interest in attending to
sounds is unusual. More frequently deaf-blind
children tend to use their remnants of vision to
auditory input can provide the children
meaningful." In spite of that I think that any degree of
auditory input they receive will never be particularly "mean-
ingful."

Deaf-blind children resist wearing hearing aids.
They actively take them off, and they do not
respond positively to efforts to teach them modes of
response with the hearing aids.

The reason for this resistance is still unknown,
but it seems that teachers and therapists have been
approaching hearing aids and auditory training
with many of these children in an inappropriate
way. Some have residual hearing so limited that the
input they receive will never be particularly "mean-
ingful." In spite of that I think that any degree of
auditory input can provide the children a constant
connection with their environment. Of the two
distance senses, hearing is the one which is the
most constant. People cannot shut their ears as they
shut their eyes: and, even during sleep, the
hearing is not interrupted. Unlike vision, which gives information only about what is in front, hearing is alert to changes anywhere in the environment. Severely deaf children should be able to derive pleasure and reassurance from sounds, even if those sounds have limited real meaning or learning potential. Awareness of sound could potentially help the children keep in touch with their environments and perhaps bring them out of a more internally motivated state.

Prior to considering any specific techniques or processes in an auditory training program, one needs to deal with the question of how to determine whether such a program is indicated at all for a particular child. A hearing specialist may like to assume that all deaf-blind children would benefit from or should be provided with auditory training; but such universal benefit is probably not the case. Whether hearing aids should be provided for all deaf-blind children or for any child in particular is essentially the same question. Hearing aids can be very significant tools in providing sufficient auditory stimulation for any deaf child and especially for a deaf-blind child, but not necessarily for every deaf-blind child. Teachers and parents must often determine whether to make the extreme effort that is sometimes required to get a child to wear a hearing aid and whether to spend the time working to develop the child's residual hearing. For which child is it important and worth any effort, and for which child is it not? Unfortunately, there are neither hard and fast rules nor a specific checklist to make this difficult decision more automatic. However, some variables and criteria should be taken into account in deciding whether or not to use a hearing aid.

The extent of the child's hearing can certainly be relevant in deciding which hearing aid to wear, but it is not a significant factor in deciding whether a child should wear a hearing aid at all. For some children with essentially total deafness, amplification seems to be appropriate and very significant. Other children with more residual hearing may be so adverse to any amplified sound—possibly because of an abnormal physiological sensitivity—that amplification cannot be reasonably considered. Amplification should be considered for all hearing-impaired children regardless of the extent of deafness unless the child demonstrates an abnormal loudness sensitivity.

This sensitivity is a physiological phenomenon that has been observed frequently in adults who have experienced hearing loss as a result of specific ear pathology. It is called "recruitment," and at its worst it means that sounds just slightly louder than those that are barely audible become physically painful to the ear. It is difficult to collect statistics regarding congenitally deaf or hard-of-hearing children who experience this phenomenon since they generally do not have sufficient language to describe it; however, I have observed youngsters become obviously uncomfortable and resist exposure to sounds that are barely louder than sounds which they give no evidence of hearing at all. This is probably a rare occurrence, but one that must be considered in deciding whether a child should wear a hearing aid.

Another variable to consider is the extent of the deaf-blind child's vision. If a child's visual modality is intact, even though deficient, and he or she has difficulty accepting amplification, it may prove more productive to concentrate efforts on learning experiences that do not depend on hearing. The amplification-sensitive child with no apparent visual capacity may require intensive, almost exclusive, attention in order to develop tolerance for a hearing aid so that some contact modality be available.

A third variable is the child's level of cognitive potential. This consideration becomes more important in deciding the objectives of an auditory training program rather than in deciding whether to initiate such a program. The profoundly retarded child may benefit from an auditory training program in a way different from that of the more cognitively normal child, but that need not diminish the potential value of the program for the retarded child.

A child's general living environment is another variable to consider. For audion to achieve relevance or importance, it should be a constant in the child's life. If the adults responsible for the child are not able to ensure consistent efforts to establish hearing aid use or if the hearing aid becomes an object of friction between the child and the adults, it may be better to emphasize other areas of growth.

Which hearing aid or other amplifying device to recommend may also depend on a large number of variables that are probably best left to the audiologist to decide. In most instances the exact specifications of the hearing aid, however, are probably not as critical as the fact that the child be provided with amplification consistently.

The first requirement for beginning an auditory training program with deaf-blind children is that the exposure to sound should be pleasurable. Secondly, the sound should be connected to some
experience that they can relate to—not necessarily an experience to "learn" from, but an experience that has some meaning for the children through their other sensory modalities. Auditory training should aim at developing hearing as a pleasure sense first, without worrying about the child's specific responses or about what is to be learned from an activity.

Movement is a tool frequently used in the training of deaf-blind children. Movement is one thing that deaf-blind children seem to enjoy consistently. For example, they frequently rock when they are left alone. Sound can often be used to stimulate this rhythmic motion. Movement can then become a natural accompaniment to their first auditory experiences. The use of this natural occurrence can be seen in the experience of Kim. At twelve years old, Kim had never consistently accepted wearing her hearing aid. She had had only a limited exposure to planned auditory training because she seemed to be completely unresponsive to sounds. During the brief periods during which she wore her hearing aid, she frequently accompanied her own rocking motions with a rhythmic vocalization, which she seldom produced except when she was wearing her aid. Her activity and stimulation were obviously very inwardly directed. However, therapists capitalized on her pleasure in this inward activity by relating it to the external event of having another person hold and rock her and humming into her hearing aid.

While more aware of the external Kim was also experiencing the pleasure she had found in her internal activity. Combining movement and sounds, then, becomes logical during the early stages of auditory training. The combination forces an intentional activity on the child, relates the activity to a stimulus outside his or her own body, and, at the same time, provides pleasure. It is the ideal time to introduce the child to a hearing aid. The coactive mover restrains the child from removing the aid, and the amplification ensures that the child receives the auditory stimulus.

After the pleasure-producing stage, the second stage in auditory training gives children the opportunity to produce sounds themselves. Hand-held, noise-making toys like loud rattles, bells, shakers, and castanets are good materials for this process. Children can experience the object tactualy as well as the cause and effect relationship between manipulating it and producing a sound. These activities can be natural extensions of earlier coactive movement activities. The teacher manipulates the children through the activity over and over again, intruding as before from the exterior to force them out of themselves. No self-initiated behavior need be expected from the children. The goal of the activity is simply to provide a pleasurable experience in connection with sounds. As a secondary benefit children may begin to associate the activity and the sound. The long-term goal of these activities is to develop an awareness of sound and the environment. A related goal is to help the children through a series of pleasurable experiences with sound to accept and enjoy wearing a hearing aid on a regular basis. Throughout this process no attempt should be made to force the children to respond or react in a particular way. The children are, in fact, relatively passive in the activity, but at the same time they are forced into contact with the external world.

The first level of listening development is alerting. Alerting can be seen in infants as their eyes widen to a novel stimulus or as they blink or cease sucking. Deaf-blind pupils exposed to more and more experiences with sound should begin to show some of these early signs of alerting. Not until these signs are evident can the pupils be expected to gain any higher level listening skills.

The second stage of listening development is searching which occurs in normal babies as they begin to associate a meaningful referent to sounds that they hear. A sound that they associate with pleasure usually mother's voice or footsteps causes them to scan their environment in search of the source, first with the eyes, then with the head or whole body. Children who cannot see will not make the usual visual-auditory connection, but they can be taught to relate a sound to a tactual experience. The materials could again be the hand-held noisemakers as used previously. When children can move the toy to produce a sound, they are ready to learn to search for the sound. Activities can be developed to allow for passive participation while guiding the children through gradual steps toward reaching for a sound with fewer promptings. Increasingly complex auditory training tasks can be easily found in several publications.

When and if sound is made pleasurable for deaf-blind children, giving them some sensory contact with the environment, the next goal should be to attach some meaning to sounds so that the children can learn and develop through...
sensory experiences. Auditory training programs that use common environmental sound sources or language that is meaningful or interesting to the child will ultimately be more successful than programs that use non-meaningful recorded stimuli or rote nonsensical exercises.

An activity inappropriate in the training of these children is practiced widely in classrooms for the deaf-blind. Teachers, often on the recommendation of an audiologist, condition children through operant procedures to respond to sounds for the purpose of developing their skill to respond to traditional audiometric procedures so that an audiogram can be obtained. There is nothing "wrong" with audiograms or operant procedures. Audiograms can be very valuable diagnostically and prognostically. Similarly, operant conditioning can be a significant tool for teachers and diagnosticians in shaping behavior. Operant conditioning can be used successfully to obtain audiograms. However, months of valuable classroom time are spent on this activity, time that is often designated as the "auditory training" time of the day but to the child is simply a pattern of meaningless behavior and meaningless stimulus, not offering any significant exposure to sounds.

How the audiometric information is used once it is finally obtained should also be a matter of concern to parents and professionals. If a child is shown to be profoundly deaf, some educators might then assume that there is no point in continuing to provide auditory input. On the other hand, a child might demonstrate a significant amount of residual hearing, leading the teacher to concentrate heavily on oral communication with a child who could learn and develop much better if speech were abandoned and a manual approach were introduced. In either case the audiogram gives just one bit of information about a child and the child's hearing. Audiologists can and should be astute observers of response behavior and should be able to assist teachers in determining expectations for a child's use of hearing without necessarily having an exact audiogram, which can take many months of concentrated effort to obtain.

Some professionals rely too heavily on audiograms. Some delay programming auditory experiences for a child through amplification or through auditory training activities pending the appearance of this esoteric document. Teachers should not risk the waste of valuable time by hesitating to initiate some auditory program for their students because they do not know exactly how well the child can hear.

Karen and Suzy are examples of children for whom it was very important to recommend hearing aids and positive experiences with sound even though there were no specific audiograms and the potential of an auditory training program was questionable. Karen was fourteen years old. She had never had any opportunity for formalized training of any kind. She was apparently severely deaf. She seldom responded to any environmental sounds though she did respond and relate in other ways. Her hearing could not be easily tested by conventional methods. She had fairly good residual vision, but it was anticipated that she might lose that vision because of repeatedly detached retinas. At the age of fourteen, with multiple handicaps and a history of very limited experiences, the prospect of Karen's ever learning to communicate orally was remote. However, her unusually positive reaction to her introduction to the use of amplification clearly indicated that there would be benefit in working to develop her hearing. The possibility that she might lose her vision in the coming years made it even more critical to help Karen establish some degree of auditory awareness and some meaningful auditory contact with her environment.

Suzy presented a different set of parameters and considerations. The recommended procedures were essentially the same as for Karen, though the long-term expectations were different. Suzy was just a year old when she was first evaluated. She had multiple physical and developmental handicaps resulting from maternal rubella. At the age of twelve months she had a very limited repertoire of behaviors, and it was not at all possible to test her hearing accurately enough to obtain an audiogram. After a few sessions of observing her behavior, it appeared fairly certain that she had a significant hearing loss though her consistent reactions to very loud sounds suggested a potential for developing more sophisticated listening skills. Suzy accepted a hearing aid happily from the start. In the absence of any structured, formalized program, her foster mother provided her with a good model of natural auditory input in association with pleasurable daily activities. From this base of general auditory awareness and acceptance, the prognosis is quite good for eventually being able to structure learning experiences for Suzy through her hearing and possibly developing some verbal skills.

The goals of an auditory training program for deaf-blind children have to be highly individualized because of the wide spectrum of conditions involved. The term "deaf-blind" is often used to include children who are visually and hearing
handicapped, but not to the point of being considered technically deaf and blind. All deaf-blind children are certainly more handicapped than the cumulative effects of deafness and blindness alone would account for; and all these children need specific educational attention, which programs designed for those with either vision handicaps or hearing handicaps alone may not be equipped to provide. Additionally, a large percent of these children have other learning handicaps. No single program or method, then, can be applicable to all of these children. Many deaf-blind children will never reach the higher level auditory training objectives because of a number of factors, including the extent of their deafness, their age when audition is first introduced, their cognitive limitations, or other factors which have not yet been defined.

Teachers should be able to consider establishing different objectives for those children whose auditory potential is limited. The first goal should be to assist deaf-blind children toward developing a sensory link with their environment and thus reducing their isolation and increasing their feeling capacity may not improve to a great degree, but then again it may. Teachers, therapists, and parents may not personally experience the immediate reinforcements that come from being able to achieve more tangible goals, but they may be able to reduce some of the frustration that often results from being unable to meet unrealistic goals. Methods of auditory training for deaf-blind children have traditionally come from procedures established with normally sighted deaf children. To the extent to which such procedures can be applied reasonably and for the children for whom they are appropriate, the established methods should certainly be used. But just as teachers and parents of deaf-blind children have developed special techniques for dealing with the other unique problems these children present, one might also think in terms of less traditional ways of approaching their deafness and helping them to utilize their hearing to the fullest possible extent. By modifying initial objectives for auditory training, teachers may find that the short-term outcomes are less immediately apparent; in the long run, however, teachers may improve the quality of a child's life and make their work more rewarding.


Ref.


Vision Training Techniques for Deaf-Blind Students

Harry Wachs
Director, Pennsylvania Vision Institute

The physiological function of the eye, the neurological function of the visual cortex, and the cognitive function of visual thinking are often misunderstood and erroneously regarded as synonymous by educators, therapists, and the lay public.

The role of the eye is to serve as an entrance port for radiant energy and then to convert this energy into neural impulses, which are transmitted through a complicated neural network to the visual cortex and other tracts of the central nervous system. The visual cortex receives, decodes, and relays the optic neural input to various areas of the central nervous system. Neural output from the central nervous system affects the musculature that focuses and positions each eye, synchronizing these actions within the eye and coordinating the movement of both eyes with other body movements. This complicated psycho-physiological process develops slowly through infancy and the preschool years and usually reaches maturity around age seven. Inadequate focus or eye movement can result from inappropriate development of cognitive schemes for ocular movement.

Visual thinking involves knowing an object by assimilating visual input, from eye and cortex, into a cognitive scheme and accommodating that scheme to the particular input. For Piaget a visual perception is primarily a cognitive mental act coordinated by mental schemes. When these schemes are used in the absence of the visual object, Piaget refers to the resulting mental representations as mental images. The word image in this context is sometimes misinterpreted as a "picture in the mind." That idea too often leads to the further misconception that the visualization process can be duplicated by a vision replica created by all other sense inputs. However, each sense input, though influenced by other sense inputs, causes its own unique mental image. There is no duplication of mental images from one sense input to another. Totally blind children cannot "see" a ball through their "mind's eye." In reality, they know the ball by manipulating it; the mental image formed is through "hand thinking." Use of the terms "mind's eye" and "visualize" are quite acceptable provided they are viewed as analogy and not as literal truth. Each sense input has its own characteristic quality and is not necessarily a "visual replica" of the object perceived.

All aspects of the experience of vision—eye movement, focus, and visual thinking—involves a process of the mind. The mind directs the eyes to move; the mind interprets the distance of the object and directs the eye to focus; and the mind knows the attributes and determines the function of the object assimilated. In Piaget's terms the mind is a totality of cognitive schemes. This process is referred to as thinking.

The mind can be influenced falsely as in any of the common optical illusions. The misinterpretations occur because they are based on existent cognitive schemes which strongly influence perceived reality. With figures such as the Necker Cube, focus changes within the eye can be observed by retinoscopic examination. This change in focus is evidence that the mind actually "sees" the planes of the square as closer or farther away, even though the drawing itself has not moved from its original plane.

And what about clarity? Is 20/20 acuity mandatory for development of visual intelligence? Heretical though it may be to other professionals in the vision sciences, the answer is no. It is true that the more clearly one can see without distress, the more efficiently that person will function; but many visual tasks do not demand precise, conjugate focus. In fact the speed reader focuses slightly beyond the page and reads in a minimal blur. Driving in a fog, a heavy rainfall, or a snowstorm, though not desirable, does not impede mobility until the external world is below minimum visibility for the visual needs of a particular driver. Accurate, precise, point-for-point focus is quite restrictive and distressful. Were 100 percent clarity to be demanded at all times, under all conditions, humans would
lack flexibility and simply would not be able to function.

For a complete understanding of visual efficiency, one must consider the significant roles of peripheral and central vision. Peripheral vision serves as a protective mechanism, as a movement monitor, and as an external spatial determinant. Central vision is used basically for clarity and critical seeing. Central vision is involved more with theoretical knowing while peripheral vision is involved more with action knowing, though both are intermingled. For survival and general life function, peripheral vision is the more crucial of the two. The retinitis pigmentosa victim is usually more restricted in daily activity than the person suffering from amblyopia (dimness of vision). Glasses that block or distort peripheral vision are tolerated much less easily than smudged or dirty glasses, which distort central vision. Increased peripheral vision is often the secret of the contact lens wearer who states, "I can see so much better now" even though central acuity is the same or, in some cases, even worse than through spectacles.

In the past a visitor to any school for the vision impaired could observe several children reading their braille visually. These partially sighted students with enough residual vision to read print were denied vision development therapy in a formalized setting, yet nurtured their residual vision by their own intelligent effort. Some became so competent that strangers refused to believe their vision impairment existed. It is the mental attitude of these impaired students that proves crucial. Limited vision gains in the intrinsically motivated individual can initiate dramatic improvement in usable vision. The converse occurs with the nonmotivated.

Researchers now have a basis for understanding the visual performance of partially sighted individuals and the social problems they encounter. The most common problem occurs when people expect too much or too little from them.

J. N., barely able to perceive light as a result of congenital impairment, had his sight surgically restored to 20/200 at the age of twenty-one. Though to most this level would be quite inadequate, to J. N. it was a dramatic improvement. With contact lenses and microscopic reading glasses, he was able to function quite efficiently. In fact, most people were not aware of his severe vision loss. A bus driver, quite disgruntled with J. N.'s inability to cope with a transfer ticket, stated, "What are you, some kinda wise guy?" and was probably convinced that he had been tricked when J. N., who had noticed his next bus coming down the street, suddenly disembarked before the originally requested stop and ran straight over to the other bus with no apparent visual difficulty.

Low vision aids are generally more effective for reading or static observation than for distance motility. Moving objects appear larger, closer, and faster when viewed through telescopic spectacles. This trait reduces their desirability as an aid for "getting around better outside" or for driving.

Why is it that some individuals function quite well with low vision aids and others refuse to use them? The first and foremost reason is variance in intrinsic motivation. But other factors must be considered: cognitive development of visual thinking (this development limits what can be assimilated); the physiological maturation of the individual; type and degree of impairment (retinal defects have a more favorable prognosis than neurological defects); and the potential of the individual to accommodate the new visual data to general movement. In fact these factors supply the basis and the goals for the vision training of individuals with low residual vision.

For many partially sighted individuals, traditional instrument vision training is of little effect. Most of the training has to be done without the instruments in a nonrestricted spatial environment. Efficient assimilation of the distance, direction, and speed of objects in the peripheral field and discernability of these objects in the central field may be developed by intervention tasks which stimulate high operative visual thinking. Such cognitive development of the visual input occurs through the following:

1. Knowledge of the incoming light's location lateral and vertically as well as its distance
2. Knowledge of how to direct and guide the eyeballs
3. Knowledge of the nature of the light (friend or foe, stable or intermittent: its color, pattern, and other qualities)
4. Knowledge of how to use the incoming light to develop a visual mental image to be used for receptive and expressive actions
5. Knowledge of how to coordinate schemes for purposeful actions of the body (movement) with visual schemes
6. Knowledge of how to utilize vision as a means of high level thinking

To effect a productive change in thinking, feedback of results is essential. Some individuals who observe mainly with peripheral vision are unaware that they do not move their eyes to fixate...
a designated spot upon request. This condition can be rectified by making the individual maintain fixation upon a convex mirror as the mirror is moved. The individual can observe his or her own reflection only by moving his or her eyes to look at the convex mirror surface. Peripheral observation on the part of the individual is not sufficient. The image in the mirror provides the feedback in this situation. A stick to touch a visually located object precisely or a flashlight to shine upon an exact spot or an electronic device which, when stimulated by touch or light, buzzes, clicks, beeps, or turns lights on or off—all those may provide feedback to the individual who has made successful fixational movements of the eyeball as a guide to arm movements.

An individual may simply be asked to describe verbally the position of an object. He or she may then be asked by the therapist to act upon the observation by walking over to the object. Such a verbal exchange can provide the individual with feedback similar to that obtained through more elaborate methods. A question such as “What is that light doing?” can be followed by requests to have the visually impaired individual make his or her light do the same. The therapist may also ask, “Is that object hot, sharp, soft, smooth, or itchy?” After answering, the individual should actually touch the object for verification. Parquetry blocks, geoboards, camouflage games, tachistoscopes, and all of the visual thinking games mentioned in Thinking Goes to School could be used to develop cognitive schemes in the course of high operative visual thinking.

In body thinking, assimilation of placement, position, and functional access of body parts is possible without visual input, even though for sighted individuals body thinking is closely associated with visual thinking. Negotiating a maze, walking on a walk rail, or balancing on a balance board while tossing a ball or keeping a balloon in the air are all aspects of visual thinking in relation to general movement thinking and readily lend themselves to high operative training tasks. These activities, though requiring a great deal of concentration, can be accomplished without visual input.

All the possibilities for developing visual thinking cannot be covered here. The creative teacher will investigate other sources and experiment with other methods. The purpose of this paper is to be a stimulation for such creativity.

Summary

Visual training of the partially sighted is feasible, and stimulation using light is basic to vision, training. Best results are usually attained by the following: (1) stimulation of peripheral fields; (2) use of techniques that require more than verbal feedback response from the individual; and (3) tasks that are kept on a high operative level to develop new schemes. Eye movements in the service of the intellect are a cognitive function and as such can be nurtured by high operative eye movement experiences.

Each eye stimulates both sides of the brain, and thus the visual input from each eye encourages development of the functions associated with different parts of the brain: speech-analytical as well as intuitive-holistic schemes. The eye itself merely serves as an entrance port for radiant energy to be utilized in the service of the thinking person inside the body.

The more body and sense cognitive schemes are available to the individual, the healthier will be his or her intellect. It follows then that every attempt should be made to encourage use of the slightest sight input even in severe cases of corneal scarring or nystagmus (an involuntary rapid movement of the eyeball). It is time to stop concentrating on the organicity of the partially sighted and to expand our efforts to encourage the individual to improve cognitive functioning through use of his or her own sense organs regardless of the severity of impairment.