Program for the Cerebral Palsied

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CEREBRAL PALSY is characterized by paralysis, weakness, incoordination, tremors, involuntary motion, excessive rigidity, or stiffness caused by pathology of the motor centers of the brain. This affliction may apply technically to adolescents, adults, or the aged. However, cerebral palsy is usually considered to mean those conditions resulting from an anomaly, injury, or disease that originates in the developing infant before or during birth or in the first years of growth (*1a*).

Damage to the brain may result in involvement of the upper and lower extremities and frequently includes the muscles of the trunk, neck, head, face, and breathing mechanism. Because cerebral injury is not limited to a single area in the brain, numerous associated defects may accompany motor involvement. These may include one or more defects in speech, hearing, or vision, mental retardation, convulsions, and behavior disorders. The classification of various types of cerebral palsy is based on physical signs. A high percentage of cases may be classified either as spastic or athetoid types. In athetosis the individual displays involuntary, incoordinate, uncontrollable, purposeless movements. The spastic condition is characterized by the appearance of stiffness. Usually the spastic is able to move the affected limb voluntarily, but the motion may be explosive, jerky, slow, or poorly performed (*2*).

The number of cerebral palsied in this country is difficult to determine. Three major studies analyzed in 1955 indicate that the prevalence rate of cerebral palsy is between 300 and 350 cases per 100,000 population (*3*). Of this number, 100 cases are under 21 years of age and 200 are 21 years of age and over. On the basis of the above figures it is estimated that the total number of cases in the United States falls between 495,000 and 577,500.

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Habilitation

Because of the congenital or early life injury, the cerebral-palsied child will grow and develop in an atypical personal and social environment. This often leads to a poorly adjusted, dependent, socially incompetent person who may be more disabled by personality deviations than by his physical or mental limitations. An individual handicapped later in life has had an opportunity to develop normal living patterns. A child handicapped throughout life has not. This factor underlines the essential difference between habilitation and rehabilitation. The development of basic life adjustment patterns as part of treatment and training is the goal of habilitation. Through this process, individuals are helped to become independent and useful citizens within the limits of their disability.

The process of habilitation must, therefore, begin early if it is to help the child develop proper habits and attitudes about himself and others which will serve as a constructive basis for adjustment to the demands of society.

It is desirable to achieve the following habilitation goals (*1b*):

- The patient should be capable of some form of locomotion, either independently or by means of crutches or other types of apparatus.
- He should be capable of self-care and self-

help in eating, dressing, toileting, and similar activities.

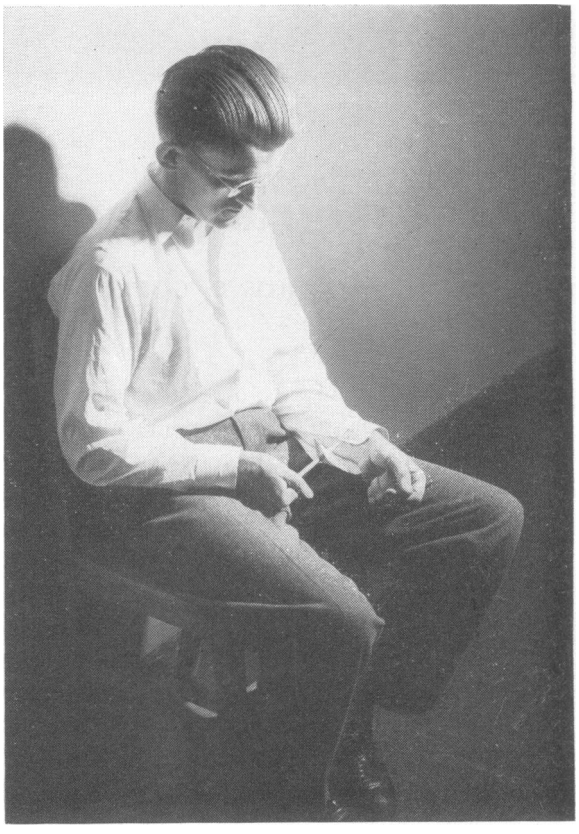
- He should possess an effective means of communication, by speech, writing, or other means.
- He should appear as normal as possible.
- He should be able to earn money, or its equivalent, through his own efforts either in competitive industry or in a sheltered workshop.
- He should be able to employ his spare time in self-satisfying avocations and in social contacts.

To achieve these goals, habilitation of the cerebral palsied cannot be considered from a single aspect. Emphasis must be placed on the problems as they affect the "whole child." Unless the medical, psychological, social, educational, and vocational needs of the individual are integrated into a program, the cerebral palsied will not be served adequately. The multiplicity of handicaps creates diverse and complex problems necessitating the provision of many types of costly services and a lengthy habilitating process. It is rarely possible for one group working alone to provide the necessary services. The responsibility for service must be shared by the individual, the family, and the community, all working toward a common goal.

Community Planning

Total habilitation requires the interrelationship of all health services. These depend on one another and must be closely coordinated to be fully effective. By utilizing the entire resources of the community, the highest potential of the cerebral palsied can be developed. Only in this manner can the economic burden on the family be relieved and the child grow up to become a productive, better adjusted member of society.

In a sound community program special services for the cerebral palsied will be integrated with the existing general health, welfare, and education programs. If necessary, the various agencies should modify existing programs to meet the needs of the cerebral palsied. One way of accomplishing this is to employ specialists in this field to work with the personnel of the general service agencies. If proper facilities do not exist or cannot be extended or supplemented, it may be necessary to establish separate services for the cerebral palsied (*4a*). However, such services should be based on need rather than on the desire of a small group to control a separate program.



A buttonhook assists a trainee in dressing. The Institute for the Crippled and Disabled makes much use of such simple devices in furthering self-care abilities.

The community plan for direct habilitation services should include—

- Help for the parents and family as early as possible so that they can learn to live with and understand the child with cerebral palsy.
- Medical services which have the facilities for early diagnosis, therapy, surgery, and general health care.
- Special educational programs that meet the needs of the child with brain damage and associated disabilities, especially mental retardation.
- Vocational guidance, training, and placement to help develop full use of the individual's vocational capacities.

• Sheltered workshops for those who cannot meet the competitive demands of industry and for those who need special work preparation.

• Homebound work programs when workshops are not available or are inaccessible.

• Recreational or diversional activities to meet the needs of those who are too disabled to perform in a workshop program.

Parent Services

Although parents are not usually considered as a service, no one else in the child's program will become more involved in habilitation. The parent might be considered as a catalyst. With proper care, favorable attitudes, support, and encouragement, the child's chances for success can be greatly enhanced. Without proper parental help and guidance, the child's chances for performing at maximum capacity will be retarded. Because the mental health of the family is a vital part of the habilitation process, it has become a requisite in the treatment of the cerebral-palsied child to clarify parental attitudes concurrently with the child's therapeutic program. If aid for the family unit is planned as part of the complete treatment program, the chances for success of the habilitation effort will be increased.

The emotional impact of having a crippled child; the feeling of guilt, resentment, and insecurity; and the practical everyday problems of raising the child must be carefully considered. Some of these problems can be alleviated through educational and counseling programs and by forming parent groups who will share the fatiguing burden of constant care and attention. Through education, parents get an opportunity to understand the needs, wants, abilities, and limitations of the cerebral palsied. The program should stress the parents' role in encouraging the child to develop independence and especially in striking a balance between too much protection and encouragement and too little. Through counseling programs the parents gain insight into their feelings of guilt and ambivalent attitudes toward their child and the reasons for family conflicts. By study, observation, and counseling they will come to see their cerebral-palsied child more objectively as an individual and as a personality. In this manner a sounder parent-child relationship can be established (*4b*).

The parents become the cornerstone upon which the child builds a foundation for adjustment. Behavior maladjustment in the cerebral palsied may result from organic brain damage, frustration caused by the handicap, or rejection by the parent, family, or society. It is, however, generally believed that environmental factors have a greater effect on personality deviations than the brain injury condition. The personality characteristics of a secure, mature, loved child may have greater prognostic significance than the disability itself. A leading medical authority in the treatment of cerebral palsy states, "As yet no one is able to prognosticate what a well-motivated child with even a severe disability and mental retardation can accomplish if given adequate treatment and parents who are interested in helping the child" (*5a*).

Medical Treatment

Treatment and habilitation of the cerebral palsied should be used synonymously. The overall therapeutic approach must take into consideration that the child has not been able to develop normally. It must, in addition to therapy, help the child gain security, promote relaxation, and relieve anxiety in both the child and his parents (*6a*).

The goal of treatment is to help the individual function as effectively as possible with special emphasis on learning to perform activities essential to daily living. The logic of the treatment aims is pointed out by Deaver. "Learning to perform the activities necessary for daily living begins as soon as the disabled person wakens in the morning. There is little value in being able to ambulate if one is unable to get out of bed, dress, or attend to one's toilet needs. The abilities to ambulate, speak, use the hands in self-care activities, write, or produce salable goods are necessary for economic independence. Education is desirable but no one is paid for the knowledge in his head. If a person cannot speak adequately or use the hands, of what economic value is an education? It is for these reasons that learning to perform the

activities essential for daily living should be the primary objective of all treatment" (*5b*).

The general methods of treatment are physical restorative services, surgery, drug therapy, and treatment for associated defects. Physical restorative services are more frequently recommended than any other type of treatment. Among these services are physical therapy, occupational therapy, and bracing aids.

Physical therapy is primarily concerned with improvement of locomotion, stretching exercises, muscle reeducation and strengthening, and improvement in balance. Occupational therapy is mainly functional. It attempts to teach and develop self-help skills and feeding and dressing techniques. This is usually accomplished through exercises designed to improve reach, grasp, and fingering abilities. Bracing is the principal method used for preventing and correcting deformities, supporting the body weight, and controlling involuntary movements (*1c*).

Surgery and drug therapy are used as aids in achieving physical restoration. Surgery is utilized only to surmount some definite obstacle to progress. The purpose is to improve functional mobility and appearance. In general, there is a cautiousness concerning surgical intervention. It has been stated that physical restoration in growing children, such as achieved by physical therapy and bracing, should always be given an adequate trial before surgery (*7*). However, there have been enough advances reported in orthopedic and neural surgery to consider it a major treatment method.

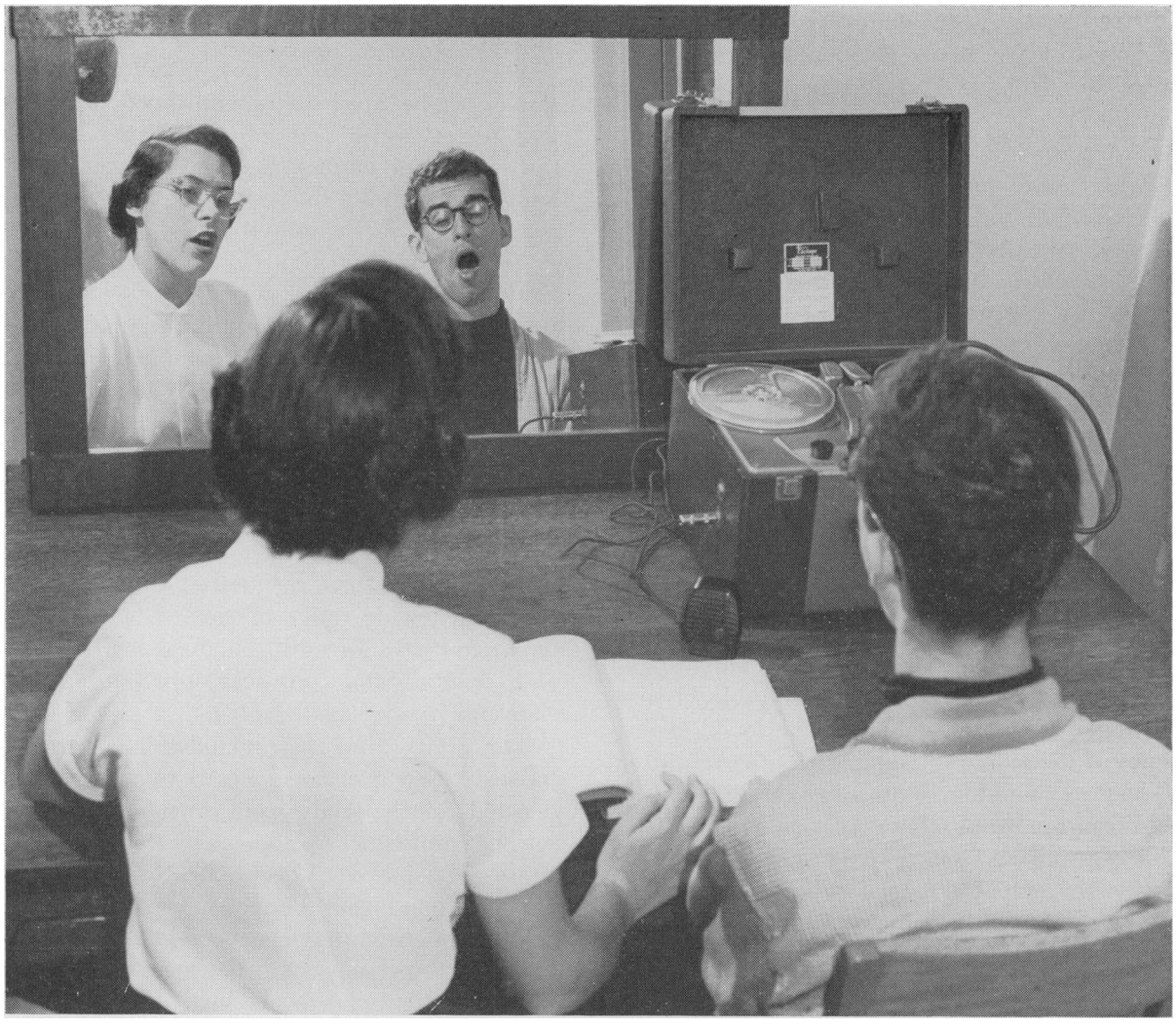
Drug therapy has been used with widely varying results for convulsions and muscle relaxation. A great deal of research is presently being conducted on all phases of drug therapy. The control of seizures through the use of such drugs as Dilantin and phenobarbital has been found effective and is presently widely used. It was found in a study just completed at the Institute for the Crippled and Disabled that certain drugs tend to relax tight or spastic muscles, making therapeutic exercises more effective. Another drug used in the same study was found to help reduce athetoid tremors and uncontrolled movements. The reason seemed to lie in its unique ability to prevent emotional tension from restricting physical performance (*8*).

Any handicapping conditions accompanying cerebral palsy should be treated as early as possible for they can seriously impair the entire habilitation effort. The child who cannot express his feelings because of serious speech involvement may find an outlet in a temper tantrum or negativeness which in turn may interfere with a consistent therapy program. Speech therapy assists the child to improve the ability to communicate by means of speech or other methods. It attempts to develop proper breathing habits and improve such secondary factors as drooling, grimacing, swallowing, and chewing. The speech therapist also gives audiological assistance to those who need hearing training. The cerebral palsied with visual perceptual impairment may have more difficulty learning to travel independently because of the inability to judge distances of an oncoming vehicle. An untreated squint, for example, may result in deterioration of vision. Qualified ophthalmological care is essential to improve crossed eyes, prevent and treat impaired vision, and relieve headaches or other results of eye strain. Dental care and nutritional needs must also receive continual attention (*9*).

The complexity of the varying handicapping factors makes it difficult to prognosticate the benefits to be derived from treatment. Parental acceptance and understanding, severity of the physical disability, and mental capacity are important considerations. Denhoff suggests the use of the pneumoencephalogram technique to determine the degree and location of brain lesions. These findings have been used as a basis for predicting potential for "good futures" (*6b*). However, he cautioned that this technique does not take into account the multifaceted problem of personality, family, or social factors, which also influence the achievement of habilitation goals.

Educational Planning

Education must be considered as part of the total habilitation process and cannot be realistically separated from other therapy the child receives. In most communities, clinic activities



Playback and mirror aid in speech therapy.

and educational programs are planned together to provide for a closely integrated program of physical therapy, occupational therapy, speech therapy, and special education. The therapists and teachers, to be fully effective, should at the same time aim at the common goal of developing a well-adjusted child as far as physical and mental abilities allow. Especially is it necessary that the educational process help establish a feeling of self-respect and self-confidence, and provide the opportunity to achieve success and gratification. The cerebral palsied must be helped to face his limitations realistically and at the same time be encouraged to utilize his capacities to the fullest.

Brain injury can so complicate the normal learning process that it is important to know about mental as well as physical limitations. By being thoroughly familiar with each child's problems, the most appropriate teaching techniques can be utilized. For example, many cerebral palsied with visual perceptual deviations have great difficulty seeing what others see when they look at the same object. It may appear distorted to the child, leading to an inappropriate or incorrect interpretation. The influence of this difficulty on the ability to read may be very handicapping and will probably affect the whole course of the individual's academic development. If this visual defect is known before assignment to a class, techniques such as special lighting or having the child hold reading material on a vertical rather than a horizontal plane may improve performance.

By recognizing the handicaps that affect the ability to learn, many personality disturbances resulting from failure and frustration can be avoided.

Another educational problem is the large proportion of mental retardation found in the cerebral palsied. An analysis of a number of studies revealed that 72 percent of those with cerebral palsy have below normal intelligence quotients, compared with 16 to 25 percent of the general population (*4c*).

Educational facilities should include a special class for the cerebral palsied who display multiple handicaps and mental retardation. Other children can be placed in special classes for all the orthopedically handicapped or in a class for the slow learner if the physical involvement is not too extensive. For those who cannot get to school because of severity of the disability or transportation difficulties, home instruction should be considered. This type of school placement is the least suitable because it deprives the individual of the social experience of meeting and being with other children. The goal should be to place the cerebral-palsied child in a normal setting as soon as he is capable of profiting from the experience.

To the extent possible, education should be directed toward economic usefulness and productiveness rather than solely toward the fulfillment of academic achievements. In order to accomplish this, a total educational program must be provided. Unfortunately, many communities provide for special elementary education but do not have special facilities for secondary education or vocational training. The individual with mild physical and mental impairment is usually placed in the regular or normal curriculum after the elementary program. However, the cerebral palsied with moderate to severe handicaps may have vocational potential if vocational training is made a part of the educational process. The emphasis in this group should be on semiskilled, unskilled, or service (porter, messenger jobs) rather than on academic or skilled-trade training. This type of program offers direction and is meaningful to the adolescent. It helps him accept his limitations but allows for training within his vocational capacities.

Vocational Adjustment

The cerebral palsied encounters many obstacles as he approaches adulthood, but few will be as disheartening or as frustrating as the search for employment. A survey of 200 ambulatory adults in New York City revealed that only 42 were employed (*10*). Two studies in Schenectady and Erie Counties in New York State indicated that 61 percent of the cerebral-palsy population were unemployed and 16 percent were employed part time (*11*). Similar results could be found in every community.

At the Institute for the Crippled and Disabled in New York City, we are investigating the vocational difficulties encountered by the adult cerebral palsied. Each individual, during a 7-week period, is given the opportunity to work at more than a hundred different jobs, covering a wide range of related employment opportunities. In addition, his social history and mental and physical functioning are thoroughly investigated (*12*).

The study thus far includes 110 cerebral palsied whose average age is 22 years. Persons selected for the study were considered to have serious employment problems by the New York State Division of Vocational Rehabilitation. It was found that 60 percent of the group demonstrated employment potential. The remaining 40 percent could not meet competitive industrial standards because of physical, mental, or emotional difficulties. Also noted was the fact that 52 percent displayed behavior deviations that affected maximum performance. The majority of the cerebral palsied studied were not ready to make the transition from school to work. They had no idea of the kind of work they could do nor did they understand the responsibilities placed upon an employee or the demands of a work situation. Anxiety concerning inability to compete with the normal population was noted in 75 percent. Undoubtedly, this was an important reason for the high proportion of behavior maladjustments.

It was also found that those in the group that did not demonstrate employment potential were more physically or mentally handicapped than the others. In addition, the more impaired group generally displayed more acute

emotional difficulties. These findings indicate that a proportion of the cerebral palsied are too handicapped physically to be able to compete under normal industrial conditions. This creates a severe and irresolvable vocational problem unless some special resource is established to meet these employment needs. In some instances this might be a sheltered workshop, a homebound work program, or, for those very severely involved, a recreational or diversional program. The study indicates that the inability to adjust vocationally is due, in part, to the lack of vocational facilities. This limitation is a major contributing factor which intensifies the behavior disorders prevalent in the adult cerebral palsied. It was noted that the young person who is severely handicapped does not display the extent of personality deviation that is apparent in the older person who has been idle for many years.

As pointed out in a previous section, there are few vocational training opportunities for the cerebral palsied. In the group that demonstrated employment potential, 92 percent had not received any vocational training, although 32 percent had completed high school. This factor is particularly serious for the habilitant whose experience is so restricted. Adequate training, even if it is at the lowest skill level, can instill in the individual a feeling of personal worth and confidence. It also can help the cerebral palsied to learn the importance of taking responsibility, of following instructions, and of getting along with others. These are basic factors in making a satisfactory vocational adjustment and are important in the habilitant's development.

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