A Perspective on Deafness and Cerebral Palsy

Alan D. Zamochnick

Follow this and additional works at: https://repository.wcsu.edu/jadara

Recommended Citation
A PERSPECTIVE ON DEAFNESS AND CEREBRAL PALSY

ALAN D. ZAMOCHNICK, M.A.

Cerebral palsy may be thought of as a neuromuscular disability consisting of motor and other involvements caused by one or more nonprogressive brain lesions (Connor, 1967). There are three main types of cerebral palsy: athetosis (involuntary movements of parts of the body); spasticity (a stretch reflex interfering with movements of parts of the body); and ataxia (a lack of balance and poor spatial relations).

Hearing impairment is most often observed in cerebral palsyed individuals of the athetoid category (Keats, 1965; Love, 1970; Vernon, 1970). Vernon (1967) reports that 51.1 percent of cases of combined deafness and cerebral palsy are caused by RH incompatibility. Another 22 percent may be attributed to pre-maturity, with the remaining cases dispersed among a number of etiologies.

A Personal Perspective

I have been diagnosed as an Rh athetoid, moderately involved, with severe hearing impairment. I had my primary and secondary education at a special public day school for orthopedically handicapped children. In most of my classes I was the one with the most severe hearing loss. During much of my schooling I was criticized time and again by some teachers for not listening, or not trying hard enough to listen or to hear. In seventh grade this situation proved a significant factor. We had a course in general science that was broadcast on television to all public schools in our city. I could not

Mr. Zamochnick is with the Office of Deafness and Communicative Disorders, Dept. of Health Education and Welfare.
follow the programs well for I was heavily visually-oriented. I could not take notes since my handwriting was at that time still laborious and difficult to read. The teacher forbade me to read the notes of other classmates for she emphasized in class that no one was to copy from others' notes. I would often be seated in the front row and would attempt to glance at my neighbors' notes to get a better understanding of what the television "teacher" was saying. When my teacher noticed this she put a stop to it saying that it was not polite to do that. I had a physical therapy session right after the television class so I did not benefit from the group discussion following the telecasts.

I constantly griped about the situation and was concerned about the poor marks I was getting on the science quizzes and tests. Also, there was very little reading material assigned to us. At last the teacher gave in half-way, after criticizing me for not trying hard enough, for not "wanting" to listen, and other things. She lent me the previous year's notebook and I had my mother type up the whole notebook. It was not of the same format, but at least it did help some. I passed the course with a low passing grade.

The next year, in Eighth grade, because of changes in the school system, we were required to have the same general science course, again from the television set. This time it was a completely different experience. First, the teacher I had in Eighth grade was the same teacher I had previously had in Fourth grade, so a rapport was very easily and quickly established. This teacher would permit me to look at the notes of other students (and by that time I had started to develop stronger peer group relationships). The physical therapy time was also changed so as not to interfere with the discussions the teacher held after the televised lessons. Also we had some assigned readings. Not only did my marks improve significantly, but also my interest in science blossomed.

This is not to say that educational television, then fresh out of its experimental stage (1961-62), was not advisable for a person with my disability; but that my experiences with two different teachers, using two different methods to deal with my situation, made a marked difference in my responses. Also, since my Eighth grade teacher had prior experience with me, she was more accessible and flexible in her approach, than my Seventh grade teacher, who had never really experienced having a cerebral palsied student with a severe hearing impairment, and who apparently expected me to act as did the rest of the class.

Some might say that the problem I have related might have been avoided had I been assigned to a school for deaf children. Unfortunately, I feel this would not have been the case. I needed the physical and occupational therapy that was offered by the school for orthopedically handicapped children that would not have been offered by a school for deaf children. In addition the speech therapy I received took the cerebral palsy into consideration, as well as my hearing impairment. Whereas in the latter I might have had, in addition to gross adjustment problems (perhaps this is
just a speculation, I really do not know), none of the physical and occupational therapy which I so badly needed. As a matter of fact, when I was in Fourth grade such a transfer was suggested, but both my physical and occupational therapists and my parents vetoed the suggestion on the grounds stated above.

Vernon (1970) points to the “educational marginality” of deaf cerebral palsied child. It is not dissimilar to the situation I faced.

“At present there are few programs designed to serve the deaf palsied child’s needs. The choice is usually between a school that meets the child’s special requirement due to his deafness and ignores the cerebral palsy or vice versa.” (p. 749)

I must admit that I was lucky to go to the school I went to, despite many frustrating experiences, and at times, almost complete hopelessness. First, no one was really quite sure whether I had a hearing impairment until after I was accepted at the school for orthopedically disabled children. When it was firmly established that I had a hearing loss, the physical and occupational therapy were already in progress, plus the school had a speech therapy department as well. Also, though I was ambulatory, I was very weak. Since my hearing loss was severe, but not profound, I could function fairly well with a hearing aid.

The problem of establishing appropriate educational facilities are enormous, primarily due to the fact that the needs of deaf cerebral palsied persons vary and the population is extremely small. Nevertheless, I am beginning to see some moves being made to assist the severely disabled hearing impaired cerebral palsied youths and young adults at the Manhattan Adult Development Center of the United Cerebral Palsy Association of New York City, Inc., under the initiative of the Adult Center’s director, Douglas E. Green. As far as I am aware, nothing has been published about this development. I worked there during the summer of 1971 under New York State Office of Vocational Rehabilitation sponsorship attempting to teach expressive communicative skills to a group of seven severely and profoundly hearing impaired cerebral palsied youth with varying degrees of involvement, using the American Sign Language for deaf people as a basic format. Although the results varied from client to client, from my viewpoint it worked quite well on the whole. These clients went through their elementary school years with limited expressive skills. The reasons for this are many, but I feel that it was the physical severeness of cerebral palsy with some of the clients, and with others, the overwhelming insistence of oral communication during their early educational experience. The area of expressive and receptive communication appeared to be clearly the most important area where work is needed with these deaf cerebral palsied individuals. I would strongly suggest the use of total communication which not only combines the oral and sign language approaches, but also takes into consideration the whole child. This is especially important with young children.
Deafness, Cerebral Palsy, and Education

We now approach the crucial question of how to cope with teaching communication skills to a deaf cerebral palsied individual. Since individuals exhibiting only soft neurological signs are not clinically classified as cerebral palsied (Vemon, 1970), the enigma would be among those with moderate to gross neurological involvement. Interestingly, Vemon (1967) questions whether the deaf cerebral palsied child has the adequate motor potential needed for intelligible speech and even for manual communication. In his 1970 study which deals specifically with deafness and cerebral palsy, he comes out strongly in favor of using all forms of visual communication to educate deaf cerebral palsied children. To this I would add typing with an electric typewriter with an elevated shield for those who cannot express themselves clearly in the language of signs and fingerspelling. I have seen several adaptations of this idea of using typewriters for expressive communication. In an occupational therapy session at the school for orthopedically disabled children which I attended, there was a demonstration of a grossly involved cerebral palsied girl (hearing) who was learning to type on an electric typewriter equipped with an elevated shield with a stick attached to her head with a band.

Speech could also be taught with some success using the combined gestural and amplification approaches for those who can benefit from it, primarily those with moderate to severe hearing impairment. It should not be forgotten, however, that most of these children have the combined speech disabilities as a result of both cerebral palsy and hearing impairment.

In my own work with deaf cerebral palsied and severely hearing impaired cerebral palsied individuals at the Manhattan Adult Development Center, I attempted to use a modified form of sign language to help the clients express their basic needs and desires. Clients more severely involved use “aids” to assist in their making a sign expression. This might include utilization of parts of the table, or even a different part of the body to help make a “sign” clear enough to indicate what the client is attempting to express. Even pointing is used when it is necessary, with the modified sign.

Receptive communication presents different problems. An athetoid like myself may need to steady his head with his hands in order to be able to follow the conversation. Similar tricks assist in reading.

In addition I have known several ambulatory deaf cerebral palsied students at Gallaudet College (interestingly, all athetoids), who were able to communicate fairly well in the language of signs and fingerspelling, though with some difficulty, due to both their newness to the manual language and the involuntary movements.

I myself, also had a lot of difficulty learning the language of signs, but as I became accustomed to it, I became so used to using it that I became practically bilingual. The more I used and practiced it, the clearer my signs would become. Many of my friends at Gallaudet remarked that I had
improved significantly during my four years as a student at Gallaudet.

The cases I have pointed out at the Manhattan Adult Development Center and at Gallaudet, were the exceptional cases. Still the discussions all point to the evolving concept that communication can be done in many forms and that a deaf cerebral palsied person, once able to communicate in whatever form he can, does a good job at expressing himself to those around him. This great impact of communication skills on an individual cannot be overemphasized, for satisfactory communication skills can be a long step forward in assisting a person in his psycho-social adjustment.

Besides being able to communicate, the variables included in developing good psycho-social adjustment, thereby increasing the chances for good mental health, are many. Among them are parental acceptance in childhood, the transition from childhood to adolescence, and employment in adulthood. Stewart (1971) has observed that:

"... the literature suggests we have given adequate attention to describing the physical basis of multiple handicaps, but comparatively little attention has been given to the socio-cultural and family interaction variables that possibly may account for the severity of many disabilities. I suggest that much greater attention should be given to these variables since they are amenable to early therapeutic intervention" (p. 1).

By far the most important variable of a deaf cerebral palsied individual's acceptance of himself lies in the familial acceptance of him as a person, as an undisputed member of the household, psychologically as well as physically. It is the family, in its various forms, with which the infant has his first psycho-social experiences. It is also during these very early years that his interaction with his family has a large share in molding the individual child into the kind of person he will become as an adolescent and as an adult, with consideration for environmental factors. This is true for all, but it becomes even more so when the individual has a physical or emotional disability. Parental counseling and discussion groups are of considerable value to parents of a deaf cerebral palsied child. It is advisable that such sessions be led by a qualified psychiatrist, psychologist, or social worker knowledgeable in factors of both deafness and cerebral palsy. It would be through these counseling sessions, and especially the discussion groups that parents could share information, feelings, and concerns about their child. This in turn can hopefully advise parents of what they can do to enrich a deaf cerebral palsied child's experiences and encourage him to try new activities and form peer group relations within the realities of the child's disabilities. At the same time such groups could encourage the parents not to monopolize the child's time and permit him to do some things for himself.

It must be noted that if a deaf cerebral palsied child goes to a residential school for deaf children or for cerebral palsied children a new set
of problems arise. The dormitory replaces the family as a central oriented grouping. Training of dormitory personnel according to Stewart (1971), has been the most neglected area in special education, especially in schools for deaf children, although it is one of the most important areas that influence a child’s life. Yet, it has been only in recent years that professional workers have began to look into this area. This is even more crucial in schools for deaf children, where the deaf child with cerebral palsy in his earlier years may need more attention than some of the other members of the dormitory population. An effort is being made at the present time by the Deafness Research and Training Center at New York University to train better, more professional dormitory personnel who can assist students living in dormitories to learn the activities of daily living (Naiman, 1972).

Adolescence and Adulthood

Can a deaf cerebral palsied individual function independently or at least semi-independently in activities of daily living? Again this depends on the severity of the deafness and the cerebral palsy. I might be biased but I truly believe that many can learn to function independently or interdependently, given reasonable modifications and time. Vernon (1970) reports results of performance tests that were given to a sample of deaf cerebral palsied students at the California School for the Deaf in Riverside.

“Based on individually administered performance type intelligence tests... the mean IQ for the 68 deaf cerebral palsied cases who were tested was 83. Almost half had average or better intelligence. Approximately one-fifth were mentally retarded. These results suggest that despite the major trauma to the central nervous system involving at least the motor and auditory areas, sufficient functioning tissues remained in most of these youngsters to permit adequate learning for the demands of daily living” (p. 744).

The importance of learning the fundamentals in the activities of daily living is crucial when the deaf cerebral palsied child reaches the adolescent stage of his development. This is a time when values in childhood are being questioned and a quest for identity sets in. To the more severely involved cerebral palsied adolescent this is not so much a problem, since he is almost totally physically dependent, as it is for those deaf palsied who are not as severely involved. This period represents an enormous change and challenge to these adolescents’ ego development. Cardwell (1956) substantiates this point:

“It is among the moderately and midly handicapped that the problems of adolescence may be the most complex, perhaps
because possibilities of maturing are better... For these children the approach of adolescence may be crucial. No longer is their dependence, normal in childhood acceptable to the outside world, yet many have had no opportunity to outgrow such dependence in their homes. Relatively adult standards of behavior prevail socially, yet these young people have had no time to learn social behavior since they have devoted the best part of their childhood to learning some degree of adequacy in walking, speech, and writing, which present no serious problems to healthy children. They have often been treated as though they were sexless and have received totally inadequate sex information. Often, too, they have had little chance to become accustomed to members of the opposite sex of their own age. Thus, they are handicapped — as would other children of such background — by a confusion about sex and by a feeling of being unlike others” (p. 452).

This identity crisis takes place in many who are considered by society to be different from the norm for their group, a question of marginality. Concerning a deaf cerebral palsied person with moderate or mild neurological involvement, it becomes a question of with which group he identifies. If the deafness of the individual is severe or profound, he is likely to consider himself a deaf individual and associate more with deaf persons, if he has been with deaf people.

From adolescence we enter into the stage of adulthood, with many new problems, social structures, and responsibilities facing us. In today’s highly competitive, highly technological world, the choice is between further academic education and vocational training going beyond secondary education. Cardwell (1956) states:

“Employment,” it has been said, “is nature’s best physician.” This has been proven many times when a youth with cerebral palsy, who has found a job which he can do satisfactorily and which... brings reasonable job satisfaction, shows a marked improvement in physical and emotional status and in speech. Productive work is essential to the economic and social well-being of the adult. It has been demonstrated that if they have suitable personality and work attitudes even some severely handicapped persons can be employed” (italics added) (p. 402).

Today, however, many places of steady employment require specialized skills and, therefore, more advanced education. The problem of finding a job for a deaf cerebral palsied individual who can function independently is gigantic. In addition there are serious questions about putting some limits on how far a person with this type of disability can be trained within his physical disability, particularly in regard to cerebral palsy.
Another subject of debate is whether it is reasonable to highly train a bright cerebral palsied person, deaf or not, who is very much dependent on others for physical needs. Wright (1960) discusses this situation in the following passage:

"There is the controversial issue as to whether people of good intelligence should be provided higher education, irrespective of their degree of physical disability. Cruickshank (1955) has spoken out strongly in the negative, arguing that "the overtrained physically handicapped person is one of the real tragedies of our time" and that such persons "will be happier if adjusted to a less skilled job than when they are frustrated in an attempt to adjust and compete in professional fields where the possibility of real adjustment is seriously limited, if not impossible" (p. 347).

Vernon (1970) adds:

"In terms of rehabilitation... vocational placement plays a crucial role. Unfortunately, employment figures for deaf cerebral palsied are unbelievably low. ... Many of these persons do lack the potential to work in competitive industry. However, even for those who are capable, who have average or better intelligence, and who have obtained an education, the problem is immense. Many with college degrees have no jobs, primarily due to poor or non-existent counseling, public attitudes, and a lack of knowledge about appropriate areas of work for persons with this multiple handicap" (p. 750).

Much more research needs to be done in the area of vocational placement of deaf cerebral palsied persons who do have the potential, educationally, physically, and socially, to do the work required in professional jobs and other white collar work. New careers are being created by the hundreds today and can be modified to suit the interests and the capabilities of these individuals. Even existing jobs can be modified to some degree to provide employment for deaf cerebral palsied persons who are physically able and have the qualifications to do the work well. These people simply need a chance, a chance to prove that they can do the work. From my observations and experiences I feel that the issue is not one of "over-training," but one of information gathering and modifications of professional and semi-professional jobs, for those who are capable of carrying out work on their own within the mainstream of the community.

The adult development centers speak for themselves. They are for those who cannot function in sheltered workshops and do not yet have good work attitudes. They are often "recreation therapy centers." I feel they maintain a sense of purpose, something to look forward to for severely involved cerebral
palsied adults who would otherwise be glued to the hospital grounds. At an adult development center, clients are encouraged to get involved with new things, form peer group relationships, and attempt to do things that are both recreationally and therapeutically oriented.

In conclusion, psycho-social adjustment of a deaf cerebral palsied person is based not only on the educational, communicative, and vocational occurrences alone, but also on how the individual views himself and his situation. He may be deaf and cerebral palsied, but he is an individual; and professional workers and teachers would be strongly advised to treat the whole person as he is, not break him up into segments and treat each part separately. By far, the most important aspect of the whole person is not the physiological, but the communicative. When a person can express his hopes, fears, desires, and opinions in a way understandable to his significant others, and his peer groups, half the battle is won. He is a part of a group, an individual, and he should be recognized as one.

BIBLIOGRAPHY

Cardwell, Viola E., Cerebral Palsy, Advances in Understanding and Care, New York, Association for the Aid of Crippled Children, 1956.


