

REHABILITATION OF A BRAIN INJURED CHILD WITH SEVERE VISUAL HANDICAP*

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General Considerations

THIS paper will present the case history of a child with severe diffuse prenatal brain damage. The purpose is not to give a thorough dynamic picture of the child's psychopathology or adjustment difficulties, but rather to highlight rehabilitation through a team work approach in which a nursery school for severely visually damaged children was used as a setting for an intricate multiphasic cooperative enterprise. The personnel were specialized nursery school teachers, a speech therapist, psychologist, neurologist, pediatrician, and psychiatrist, with the social worker, as coordinator, being responsible for planning and carrying out the total program.

The main problem for this child with a severe visual handicap and diffuse brain damage was the introduction of structure into the environment responsible for his upbringing.

We consider environmental structuring as one of the most important factors in planning for the brain damaged child. Structured settings help this type of child to be less anxious. In our nursery school it was necessary for the teachers to use a special approach in handling Jackie. He needed more firmness and

occasionally even physical restraint. We demonstrated to our staff that one does not have to give less if one restricts permissiveness. For instance the prohibition of the use of primitive speech sounds in the nursery school helped the child to learn common language. The application of this principle promoted greater progress in behavior and in learning.

We are aware that the use of relationship is a common element in both teaching and psychotherapy. A child who becomes attached to an adult gives up unacceptable behavior in order to please the adult and to protect himself against the threatening loss of this person. In order to understand this, we must know the psycho-biological process of personality growth which in the brain damaged child is basically the same as in the normal child.

The human newborn is dependent and unable to do anything for himself. His psycho-neurological system is undeveloped, and all his movements are at random, without intent. He would be unable to survive unless cared for by adults. The human newborn is functionally far below other newborn mammals, but after three years the child is far advanced beyond the animal level. The explanation for this undeveloped state of the newborn's psycho-neurological sys-

tem seems to be that in order to be man and not animal, early exposure of the fetus to human environment is necessary. The bearing time in man is short in comparison to his size among the mammals. In order to achieve full neuro-psychological function the human young has to be exposed to the human environment in an immature state so that he can develop whatever cannot be achieved intra-uterinely. The baby becomes integrated into human neuro-psychological functioning through environmental exposure. If not so exposed, the pathways for learning and development of emotions and judgment are left undeveloped. The neurological system of the newborn is probably not organized for rigid specific function but certain integrative processes seem to be bound to specific timing and maturational processes of the nerve cell.

The young child will be inclined to act savagely if permitted. There is seduction of the child by the mother's cuddling and fondling. This brings the child into a dependency relationship which he cannot give up by himself. He will therefore sacrifice part of the "savage id" for the mother's love. The development of the super-ego starts with accepting the rules of the adult for the sake of gaining love and security. The super-ego is at first ego-alien and becomes ego-syntonic by upbringing. Continuous absorption of environmental culture continues through childhood. Intimate relationships between individual and environment are necessary for growth because nothing happens without stimulation. If we want a child to function we must stimulate the child. This applies to all growth processes in nature.

In some areas early specific stimulation must be given (as for example in music) whereas in others stimulation does not need to be specific. A great deal of function is developed from unspecific stimulation, but stimulation is nonethe-

less necessary. Because it is difficult to speculate upon how far we can help a specific brain injured child to function in society, it is a most damaging attitude for the consultant to suggest a poor prognosis early and not to wait and permit the child to be exposed to an increasing variety of stimulations and experiences.

The problem of establishing an exact topographical diagnosis of brain damage is always difficult. When there is reason to believe that neurological damage exists, teachers and social workers do not need to adopt a specific attitude different from that which we take toward the autistic or schizophrenic, i.e., firm but not hostile; warm but not over-protective; stimulating without pushing. There is only a fine line of distinction in these approaches. The professional adult has a number of conscious and subconscious clues in order to control his own attitudes; the adult's frustration tolerance is important. One should check and recheck one's own attitudes frequently when working with severely disturbed and brain damaged children; whatever we do with them should always have purpose and be goal-directed. It is dangerous to do things with people without knowing why we do them. As professionals we can not permit our unconscious to act out in relation to these children.

Specific modifications of behavior or methods are not needed nor indicated for parents or teachers, but we should be aware of quantitative differences. We have to provide specific stimulation to help a child to catch up but we should never push. It is dangerous to assume that neurological damage *a priori* limits severely a child's chances to respond to our efforts. Overemphasis on the organic aspects of a child's behavior in a nursery school can increase the damage since we can not assess the amount of permanent handicap until we have made all possible efforts to help the child. An

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early pessimistic attitude limits our own effectiveness.

All neurological damage in a child becomes heavily overlaid with emotional difficulties, beginning with the child's first day of life. These emotional difficulties have a very realistic background. They have two main roots:

1. The brain damaged child needs to adapt to an environment geared to a non-damaged child.

2. Severe reactions of any parents to brain damage in a child are to be expected. Social agencies and teachers never deal directly with brain damage but with emotional reactions of child and parents to the brain damage.

Case History

Jackie first became known to us at the age of three and a half, when his mother requested placement in our nursery school. At that time Jackie's vision was apparently impaired. He had no speech. He was only partially toilet trained and still drank from the bottle. His activity was scattered, he was easily distracted and disoriented. He was, however, extremely involved in repetitive behavior.

The family consisted of Mr. and Mrs. B, both 47, and Jackie. The B's were married when they were 33, a first marriage for Mr. B and a second marriage for Mrs. B. Mr. B is a college teacher, Mrs. B also teaches. Their income is modest. Both parents are bright and socially alert. Their interests lie in intellectual and cultural fields. Very eager to have children and concerned about their own age, they tried to raise a family very early in their marriage. Mrs. B had three miscarriages within the first seven years of the marriage. When she conceived Jackie, Mrs. B began prenatal care in the second month and was "super-careful" throughout her pregnancy. Mr. B was both anxious

about the pregnancy and restless in relation to his wife's over-cautiousness. There was nothing significant in the pregnancy history. Jackie was born at term, by low forceps delivery after eight hours of active labor. He weighed six pounds, 11 ounces. The child was moderately jaundiced at birth but otherwise his physical condition was good. When he was about three months old, the mother noticed a fluttering of the eye balls and difficulty in focussing. From that time, the parents sought a series of medical consultations regarding the eye condition, culminating in hospitalization when he was 9 months old. At that time the ophthalmologist diagnosed the condition as a congenital nystagmus of unknown etiology. The neurologist had the impression of cerebral agenesis (abnormal or imperfect development) with mild mental retardation and poor vision; but neurological examinations were negative. (We are not presenting the complete and detailed diagnostic material.)

When Mrs. B applied to the agency, although she was most astute in her observation and evaluation of Jackie's development, her recall of his early development was almost entirely blocked out. From the time that his visual defect and later the mental retardation were discovered, her entire focus was in these areas, and she gave little thought or attention to development in areas that did not directly contribute to an estimate of Jackie's mental and visual capacities. Early motor development was apparently normal, he was walking by 17 months. There was a good deal of head banging in response to frustration but also "without reason." He seemed occasionally withdrawn, laughed a good deal in response to appropriate stimulus but could not make his wants clearly known.

Just before coming to us, the mother had been engaged in a series of fruitless attempts to arrive at a clearer under-

standing of the nature of the child's problems. She had a deep sense of disappointment in his failure to develop. Most nursery schools would find him impossible to absorb into its program because of his atypical bizarre behavior. The child obviously had a considerable amount of useful vision, although it was not possible to gain enough cooperation to assess the exact extent of his vision. Nonetheless, we felt that it was valid to accept Jackie in our nursery school in order to determine, through observation by the team of nursery school teacher, pediatrician, psychiatrist, psychologist, and social worker, his level of functioning and his potential for growth when exposed to a relatively protected setting.

The nursery school at the Guild had been established in 1951 because of the growing problem of children blind since birth (many with retrolental fibroplasia). Over 90 per cent of these children were one to three months premature, and there was serious brain immaturity in many of them. We had therefore selected a pediatrician with considerable experience in neurology; there were also a child psychiatrist and a speech therapist on our staff.

When Jackie entered nursery school, he was described as "a slight, thin, wiry child; his eyes which are large and black are crossed and unfocussed." In the nursery school, the teachers were not aware of any visual impairment; his primary means of identification were visual; he would go directly toward an object he wanted, and was interested in colors. He was able to separate crayons or pegs into groups of colors and used visual cues for toys such as rings, nesting boxes, etc. He did not bump into things, nor did he use non-visual senses for primary identification. Jackie had no recognizable vocabulary and expressed all his needs through gestures or sound. It seemed as if these sounds were variations of the same hoarse cry

but within two months the teacher had observed that while counting or trying to name colors, he would use different sound combinations. These sounds were "Ba," "Gi," "Ma," "Pa," in different pitches, and had no observable relation to words which designate these objects.

His hearing seemed to be normal but he did not indicate an acute awareness of sound. He concentrated intensely on any activity in which he was engaged and there was a lack of response to other stimuli. For example, when listening to records he did not respond at all when his name was called. He seemed unable to respond to more than one stimulus at a time. Despite this apparent concentration he was easily distracted by small or irrelevant details, so that he would perceive a small portion of a picture but would not take in the whole. He rejected most of the play material presented to him and resisted routines.

The psychiatrist who observed the child at this time found that Jackie was hyperactive and restless. He generally appeared preoccupied with some purposive activity which was somewhat scattered from moment to moment, but he seemed fully absorbed at the time he was engaged in it. He showed mild resistance to doing things he did not choose and moderate irritation and frustration when he could not communicate his needs to others. No real anger was observed, and he rarely appeared fearful. There was a very marked insistence on routines that he followed in a stereotyped manner. There was little evidence of object relationships. Jackie did not discriminate in his approach to adults, using them for his own needs and not especially distinguishing among them. He ignored other children unless they got in his way, at which time he pushed them away. There was no real anger displayed when he behaved aggressively towards other children, but there was no attempt at self-control. He appeared

quite ruthless and indifferent when he was hurting them.

He learned by means of constantly repeated routines. Once he mastered them, he could then move on to slightly greater flexibility. He showed little evidence of creativity or imagination. He resisted learning by insistence on doing what he knew already, by restlessness, and by the strict adherence to compulsive routine. His lack of speech suggested a motor-aphasia and there was the possibility of visual impairment on an organic level; the lack of smoothness and coordination in his gait was also suggestive of organic neurological damage. He seemed to have a disseminated type of congenital neurological disorder. The neurologist admitted a slight possibility of reversibility.

Above and beyond the organic features noted, there were many signs pointing to emotional problems. Jackie's insistence on routines was interpreted as the attempt of a child with organic impairment to master his environment on the level of which he is capable. When he learned something he got gratification from it and was reluctant to relinquish it for newer and more anxiety producing experiences. His hyperactivity indicated anxiety. It seemed probable that he had fear in relation to new situations which he could not yet master, and that there was much frustration involved in his not being able to express himself and his wants verbally. His self-absorption seemed a defense to close out new and frightening stimuli. The emotional problem was marked by considerable anxiety in new situations and a hesitation to move ahead on the basis of his own proven capacity.

Therapeutic Approach

As soon as our team had worked out and agreed upon the diagnostic concept as outlined above, a program was established for a coordinated therapeutic approach to be carried out through nursery

school, speech therapy, and work with the parents.

In working with him, the teacher introduced routine procedures one at a time and insisted that he go through them with her. For example, she sat him on her lap at juice time and did not let him go until he held his juice cup. Each new routine met with resistance expressed by scolding noises or trying to get away from the teacher. This resistance did not continue for very long. Once he accepted routines he needed to have them reapplied compulsively in the same sequence. For instance, he would at first urinate only in the third toilet bowl or use crayons exclusively at the table where they were originally presented to him. He became somewhat less rigid in his demands as he became more familiar with the situation. With each new experience he needed his special teacher to go through it with him, but once it was established he would accept help from other members of the staff.

The environmental handling seemed of primary importance in this case. We thought that a structured setting would help the child to feel less anxious and then to be better able to absorb the learning material we and the home had to offer. It was necessary to advise the teachers to change their approach to this child. All of our children need stimulation, encouragement, and exposure to experience, but Jackie required in addition a certain amount of physical restraint and a less permissive attitude. During the ensuing two years the teacher found that Jackie responded well to routine, but that he could accept change if his resistance was physically controlled in the beginning stage. What he learned did not come simply from exposure to new things or his own exploration but from having to accept certain habits and skills through firm and consistent insistence from the teacher that he use and master his skills. When the

newly learned function did not use all the possibilities that the material had to offer it was necessary to go through the same learning procedure again in order to improve his mastery of the material. Jackie was not able or willing to do this without constant prompting.

The following shows his response to the learning situation:

Jackie was markedly disturbed by accidents of dropping and spilling. Whenever such an accident occurred, he began to screech and to kick his feet loosely in front of him. If seated, he would push his chair back noisily, jumping up and down on it; several times he fell to the floor. He seemed completely unable to control this kind of acting-out of frustration. If asked in a friendly tone, "What is the matter?" he replied verbally only if held firmly and quieted by the teachers. He would then point, saying in a loud screeching manner, "ah, ah," even at a time when his language had already developed considerably. At first, the teacher's request, "Pick it up Jackie," would only lead to more violent screeching. The loss through dropping the object precipitated a frustration reaction of total panic and disorganization, much like that of the newborn infant whose homeostasis is disturbed. It was apparent that he had not yet learned the connection between object-loss and his actual potential ability to pick things up and repossess them. He needed help. The teacher showed him again and again how to pick up the article. Then she put it back on the floor for him to pick it up himself. His frustration seemed to be all the greater, and he kicked and screamed more wildly than before. It was necessary for the teacher to take his hand forcibly. At first he resisted with all his strength. She put his fingers around the article saying, "Pick it up," then raised his hand above the level of the table, opened his hand and dropped the article onto the table saying, "and

put it on the table." As Jackie and the teacher worked on this single problem for about three months, Jackie was able to do progressively more for himself. The use of the words, "Pick it up and put it on the table," in a particular rhythm and tone seemed to help Jackie to perform his task. The teacher later observed him picking up pieces of his favorite game or blocks while he repeated aloud this formula. The teacher then moved to the next step of requiring Jackie to tell the teacher what was disturbing him when he screeched. For some weeks she said, "Jackie has dropped the pegs" requiring him to repeat it before going ahead with picking up. After he had said, "Drop the pegs" the teacher would say, "All right Jackie, pick it up and put it on the table." He then moved on to say, "Jane will do it," and a new reply was added by the teacher. "No, Jackie will do it, Jane will not do it." The last step in the learning process came when Jackie said teasingly in the middle of the procedure, "Jane will do it," but added quickly, "No Jane will not do it, Jackie will do it" and returned to the table to do it by himself. We have given this example in precise detail to demonstrate how learning took place with this child. We made use of what is usually considered a psychopathological, compulsive-ritualistic way to master function; we introduced this mechanism consciously and in full awareness of the fact that we would have to wean the child from this device again at a later date when he would not (and actually did not) need it any more.

The reasons why our team approach in teaching was successful and brought a large amount of recovery to Jackie—more recovery than we had expected—are manifold. First, our nursery school teachers have broad experience with the day-to-day teaching of simple routines such as chewing, self-feeding, talking and the use of large and small muscles. Be-

cause blind children are not exposed to the extensive stimuli which come from the outside world through vision, they are not able to learn on the basis of visual imitation, and their development is slowed down. The parent of the blind child often is confused about how to teach a child who cannot be shown how to do things through visual demonstration. Secondly, there is very close cooperation between the various disciplines: nursery school teacher, speech therapist, social worker, psychologist, and psychiatrist. This makes possible an intricate process of regular cross stimulation and re-evaluation of the youngster's growth and of the teaching methods used. This reduces the incidence of depressed feelings and discouragement among staff members when progress appears slow or nil. The interdisciplinary approach provides a much larger amount of resourcefulness and cross-fertilization in the teaching process. Thirdly, we did not attempt to bind ourselves to a definitive prognosis at an early date. There was definite temptation to resign ourselves as individuals to the "fact" that this child could not learn any more, but careful observation and interdisciplinary evaluation made it possible for the team to continue in a consistently constructive framework and not to give up prematurely.

Finally, the team working with this child has had broad experiences with children having organic brain damage because of the nature of the precipitating factors in early infantile blindness. Our nursery school has a large number of children, who had premature birth and who required prolonged incubator care in order to preserve life. In the incubator, these children were exposed to a high concentration of oxygen which in many cases resulted in retrolental fibroplasia, i.e. partial or complete destruction of the child's vision. While the medical profession has in the last

few years been able to control the cause of retrolental fibroplasia, our nursery school population still includes many prematurely born children without vision who also suffered various degrees of damage or underdevelopment of their brains.

Speech therapy has followed closely the methods established in the nursery school. Jackie at first resented the therapist. He gave the impression of resisting any effort to draw him into a pattern of communication when he became aware that the therapist was working toward this. He was however able to follow directions, to focus his attention for short periods, and to emulate sounds. He has been treated by regular sessions twice weekly. Within a year's time he has been able to accept formal correction of his speech defects; he moved from ritualistic repetition of words and phrases to initiating his own phrases and finally to sensible and uninhibited replies to questions directed at him. He is now beginning to relate one lesson to another and is taking the initiative in correcting defective sounds, using newly learned techniques. His speech can now be generally understood.

Casework with father and mother has been directed toward helping them to understand and to work through their feelings about Jackie's bizarre, atypical behavior. They also accepted methods of handling him as they were developed in the nursery school. The mother is an ambitious woman who conceived of bearing and raising her child as the central focus of her life. She had found it quite painful to accept her difficulties in carrying pregnancies through to term, and she described how amazed and delighted she was when she finally had a normal delivery. Her distress was great on learning of Jackie's visual defect, witnessing his slow development, and being told that neurological damage was great. It was magnified by her serious

problem in fully integrating this knowledge. In the main she has utilized defenses such as changing from one consultant and from one agency to the next in rapid succession and attempting to place herself on a professional level with those whom she consulted. She has recently begun to share more of her pain with her caseworker and to face her fear that she is actually unable to handle her child. For a long time she made no demands on him on the theory that disappointment resulting from his inability to meet her demands would be too much for her. She is now firmer and more consistent. She has recently planned to go away with the child to the country, which means exposing herself and the child to a group of other parents for the first time. This progress was achieved when she accepted the fact that the child has diffuse organic brain damage but that he is nonetheless able to learn. She now recognizes her own emotional conflicts which have prevented her from providing the child with firm structures and handling. She no longer has as great a need to deny the problems by presenting herself as another professional person considering an objective matter. Her frantic shopping for resources has ceased.

In the past 6 months, Jackie's growth toward socialization and verbalization have increased at a rapid rate. He is now using his speech to establish relationships with other children, his attention span has increased quantitatively and he uses a much greater variety of toys and materials. He has begun to learn to control his approach to other children. Roughhouse activity is changing to teasing, and he has learned to avoid hurting others. His emotional outbursts are less frequent and less intense. He can accept

limits, and tries to make fun of his reactions to frustration so that they can become acceptable. The nursery school is of course still aware of his continued need for structure, but we find Jackie's atypical behavior considerably easier to deal with; he is a much more relaxed and a happier child.

Summary

This paper discusses the values of the team approach in the nursery school teaching of a child with diffuse brain damage. Our work with this child involved the application of more physical restraint, more structure and a less permissive attitude in the teaching situation. We consider it dangerous prematurely to assign a poor prognosis to the brain injured child. It is fallacious to assume that neurological damage *a priori* limits the child's chance to respond to stimulation. The approach to the child should be essentially firm, warm and encouraging. The team members should be aware of their own frustration tolerance. They must understand their own reactions to the child's need for physical restraints, as demonstrated by the situation in which the teacher taught Jackie how to pick things up despite his severe panic reaction in the face of this threatening new experience.

Environmental structuring at home and at school was one of the most important factors in the treatment process. We established a moderately permissive but giving approach. We cannot prognosticate at this time the maximal degree of integration, but we do know that Jackie has made good, often surprising, forward steps and that he is now ready to move into a more formalized learning situation.