

**SECOND SESSION****The handicapped in society**

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Adolescence is a period of transition between puberty and full maturity; physical changes occur during this time and considerable emotional and social adjustments have to be made. This definition is used in order to emphasize the *changes* which are occurring and the fact that all these changes are leading towards a state of greater maturity and independence. This is a period of stress for many children; particularly for those who are handicapped.

Let me now turn to the definition of a handicap. In a recent medical article the author pointed out the origin of the term, handicap, from the expression 'hand in cap', the idea being that disabled persons had to solicit help by putting their hand in the cap in the hope that there was some money for them, but it was a great gamble. A handicapped person is one who has problems and is in need of help and assistance. Handicapped children often have problems of a very complex nature which need more intensive study and scientific analysis than they usually have received in the past, and the help they receive must be more adequately organized than on the basis of a lottery!

**Incidence of handicap**

It is difficult to give a precise figure for the number of handicapped adolescents since it depends upon the extent a person has to be handicapped in order to be included. Various figures have been quoted, and a prevalent one is that one out of every ten children is handicapped, and half of them are handicapped to such a degree that they need some form of help. If we include only those with very severe physical, emotional and mental handicaps, the incidence drops to 1-2 per cent.

Doctors in practice are concerned with patients who seek their attention, and may be unaware of a number of the handicapped adolescents who do not have acute conditions, and manage in one way or another, and so do not come to their doctors' notice. This introduces an interesting point—how far should we, as doctors, search out these children who have problems and need help? To what extent are we pre-occupied with the practice of acute medicine, how much can we be concerned with the practice of preventive medicine and with the health of the community as a whole? I suggest that as physicians we have to be concerned about the health of the community and determine the numbers of handicapped adolescents in need of help and see that they get it in the right way at the right time. You may consider that this can be of interest to the few who want to deal with handicapped children, but should not concern you as a general practitioner, but the parents of these handicapped children were themselves adolescent not so very long ago, and some of the adolescents you are seeing now will in turn have the unfortunate experience of having a handicapped child. Whenever we see an adolescent it is perhaps worth while thinking whether this person is going to be able to cope with some of the problems which might arise in such a situation.

**Puberty**

Most handicapped children experience puberty in a normal way, but in some cases puberty occurs either very early or very late. For example, precocious puberty may occur in cases of treated tuberculous meningitis, or of hydrocephalus, whilst

delay in the onset of puberty and all the subsequent adolescent changes is seen in other handicaps.

### *Physical changes*

A considerable growth spurt and change in physical structure is characteristic of this period. Variations of the normal pattern such as excessive or restricted growth and early or exceptionally late growth all lead in their own way to embarrassing situations. For instance, the exceptionally tall or short person in the class is so distinctive from his peers in physical stature that he has difficult situations to deal with and for a period is handicapped in this way in addition to his other handicaps.

Children often grow 4 or 5 inches in height during this period within the space of a year and this marked growth leads to complications. It is not uncommon to see handicapped children during this period become excessively tired because of the strain of coping with the combined demands of their physical growth and learning as well as their handicaps. Children with physical handicaps are predisposed to the development of deformities and they may experience an aggravation of their deformities as a result of their rapid growth. For example, a child with a slight equinus deformity of the foot or a mild scoliosis may experience deterioration of the deformities within a few months, and may even come to require surgical help. This means that any handicapped child liable to have a deformity must be subject to increased vigilance during this time. I have known children who were admitted to hospital for a relatively minor procedure and the immobilization combined with the rapid growth has been sufficient to aggravate a deformity and produce quite hideous defects. One child with hemiplegia had an illness at the age of 14 which kept her in bed for two or three weeks, and at the end of that time had developed a serious scoliosis, and she became a severely-crippled child.

### *Emotional changes*

Characteristic of this period are the increased self-awareness, the need to conform to the group and to have their peer's approval, the drive towards independence, the need to rebel against authority, the idealism, and the development of sex drives. These changes and adjustments may prove difficult for non-handicapped children, but for the handicapped a difficulty in balancing their needs and their drives on the one hand and an inability to express these needs on the other hand sometimes leads to extreme frustrations. For example, one girl was practically immobile and as a result was completely dependent upon her very attentive and kind parents. She was beginning to feel a need for independence and was unable to obtain it, except by forcing herself to vomit whenever she wanted to alter the situation.

In order to help adolescent, handicapped children we need to create situations in which they can occasionally rebel, situations in which they can excel at something which gives them satisfaction, and opportunities to increase their daily experiences.

Contact with other individuals is important. Non-handicapped children learn a lot from contacts with others. Dr Warren described how his son and his friends talked amongst themselves in their daily contacts and so reached understanding of many of their problems, but how can a child obtain this understanding if he has difficulty in communicating with his friends, or if he is unable to contact children of his own age and of the opposite sex? Handicapped children are deprived of all these experiences. It is not easy to provide some of the necessary experiences, but I have seen some examples of what can be achieved. One example which impressed me a great deal was in a hospital school where there were a lot of adolescent handicapped-children and in the evenings and at weekends several of the students from a nearby college came along and acted as brothers and sisters to these children. It brought to the children a breadth of experience which they would not have obtained in any other way and it was also very valuable for the students themselves.

Another example was the creation of a youth club for handicapped children which began when we wanted to know what had become of a number of handicapped children, mostly children with cerebral palsy, who had been seen at the Children's Hospital in the past and who were now well into their teens and reaching adult life. We found that many of them were just sitting at home doing nothing. The arrangements which had been made when they left school had fallen down. Their parents did not know where to turn for help and had no realistic ideas about helping them so that they were continuing to do many things for the children and were not stimulating their independence. These children who had been under active hospital care a few years earlier were now just languishing in their homes. We started a youth club gradually because we realized what a task this was going to be, and as the years went by things seemed to work successfully and the club went from strength to strength. It was quite remarkable to see what could be achieved. These abandoned handicapped-adolescents were becoming individuals again and were learning to do things; they had been rejected, they were unsuitable for competitive employment, they could not be fitted into any scheme, and yet within a matter of months they were going on camping expeditions, they were competing for the Duke of Edinburgh Youth Club awards, and they were organizing their own dances and club activities.

Many of these children were in wheelchairs, but this did not stop us arranging a holiday at the seaside with normal children from other youth clubs. When one of the parties arrived at this holiday centre the attendants were horrified because, not realizing the extent of incapacity of a plump girl in a wheel chair, they had put her up on the third floor. This problem was rapidly solved. A few of the boys from another youth club carried the chair and the girl to her room and this continued throughout the two weeks she was at the centre. This proved to be a most useful experience both for the boys and for the girl, without which she would never have had contact with the boys and the boys would not have appreciated the girl's difficulties. This accidental mismanagement proved to be a valuable experience, but it is difficult to plan this sort of thing in advance. It does prove, however, that we should not be too rigid and stereotyped in making plans for handicapped children.

### *Social aspects*

Socially-handicapped adolescents are in a dilemma. On the one hand, there is their drive towards independence and desire to go out into the world, and on the other hand it is doubtful if the world is ready to receive them. If all our handicapped children are segregated in special schools during their school years are others going to understand and accept them when they see them in adult life? Life is not easy for the handicapped. My journey from the train to the hotel last night illustrates the complexities of modern life and the difficulties facing any handicapped person. When I got off the train there was a long walk along the platform and up the stairs to the exit. How could I have managed this if I had been handicapped? There were a few taxis about, but not one of them was capable of taking a folded up wheelchair in the boot. I arrived at a nice new hotel where I had to get into a small lift which would have been difficult for a child with any visual or auditory handicap to understand, because the door slammed and there was inadequate indication as to what was happening. I made a telephone call requiring a seven-figure sequence which would be too complex for many intellectually-handicapped children.

So as our society becomes more complex, we are making it more difficult for a handicapped individual to join it, and I suspect that in many cases we do not really welcome them or accept them. We must plan for their needs; there are many instances of failure to do this. For example, one tall, handicapped boy who requires a wheelchair illustrates the social difficulties arising following a period of rapid growth. He still has to sit in his old wheelchair which is now much too small for him. His feet

are going over into a deformed position. He no longer likes to go outside the house and meet people. For a child who has got to live every day of his life in a wheelchair, it must be realized that it is part of him and his personality, and if he is to mix socially, he needs a good, efficient chair of the right size. Another example is that of a boy of good intelligence with athetoid cerebral palsy who has difficulty in speaking, has to be fed and is now needing to be shaved by his mother. How does a child like this achieve his independence when so much has to be done for him? Surely it will help his social adjustment if we find some way for an intelligent child like this to do at least something for himself?

### **The need for continuing care and training of personnel**

The problems of the adolescent, handicapped child do not begin in adolescence. The care of the handicapped child begins in the early years and it has to take the form of continuing care. During these years the child comes into contact with many people, general practitioners, school doctors, paediatricians, surgeons, teachers, nurses, and therapists, and all their effort and work is being directed to producing as full and independent life as possible for the child when he reaches adolescence and adult life, and what happens in the early years determines the success of what happens later on. The parents' own attitude following the initial interviews when the handicap is discussed with them for the first time determines how much they are going to over-protect the child, and deny him the independence which he needs so much.

We need to introduce into our teaching of medical students a much greater understanding of the needs of the individual, which is well illustrated by the care of the handicapped child. We need to provide more postgraduate training in this connection. We need to be able to help people deal with parents, for the quality of parent guidance is reflected throughout the life of the handicapped child. More than anything else we need to think carefully of how we can produce and train the professional staff who have to take clinical responsibility in the community for the problems of the continuing care of handicapped children.

## **Discussion**

**Question:** Would it be reasonable to give a mentally handicapped adolescent girl the pill as a routine, both to prevent her from having children should she be abused, and to enable her to lead a happier life should she later on find a male companion?

**Dr Holt:** I don't think that mentally-handicapped girls are taken advantage of anywhere near as frequently as is often thought to be the case. There is no reason why the pill should not be used if this was considered desirable in any particular case, and I know several cases where this is being done.

**Dr Dimock (Shepton Mallet):** Would Dr Holt say something about deaf children. I went to a deaf school and found that the children passed very few 'O' level examinations, and I am interested to know what happens to them when they are older.

**Dr Holt:** In the past we have concentrated too much upon the hearing deficit of the child; we make a diagnosis of deafness, supply a hearing aid and then sit back and feel that we have solved the problem. In fact we should concentrate more upon the child's language and speech development; if we checked the progress of this aspect, we would