

Attitudes

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**PRACTICAL DIFFICULTIES ENCOUNTERED
BY PARENTS OF C.P. CHILDREN**

Mithu Alur



REFERENCE



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A considerable amount has been written about various aspects of life with a cerebral palsied child. We know that a condition such as cerebral palsy needs a large team of specialists and during the last few years one has come to realise that a very important member of the team is the parent. It is a well-known fact that the co-operation between the parent and the specialist is a vital factor in the development of the child's abilities. I would go as far as to say that the parent is in a way a specialist, for only he or she holds the information about the cerebral palsied child's difficulties at home, and a parent is best able to tell us what his needs are and what will alleviate such difficulties.

This paper is about the practical difficulties faced by parents of cerebral-palsied children and is a result of numerous sessions with parents in individual meetings, group workshops and seminars. Some of comments are based on a study of parents I carried out at the Institute of Education, London University.

I have looked at three areas affecting the family and the child during the period between birth and five years.



REFERENCE

Much has been written by professionals and very little by the people who are directly concerned. Therefore, I submitted a thesis which highlighted an aspect which had hitherto been neglected. I decided to report what these parents actually said when questioned about the difficulties they encountered.

IMPACT AND TIMING OF THE DIAGNOSIS

When asked about the impact and the timing of the diagnosis, there was a strong feeling that parents should be told the truth as soon as possible. Yet I do appreciate that perhaps the most difficult task for the doctor is telling the parents that their child is a spastic, quite apart from the difficulties inherent in making a confident diagnosis of the condition of cerebral palsy in the early stages of a child's development. Frequently, the mother's fears about their child's development were brushed aside and it was only after one year of running to and fro between home and hospital that they were told that their child was a spastic. One mother said that "I was told that he had minimal brain damage, but I didn't even know the effects of brain damage, nor what it meant".

Another mother said that "If only the doctor could be a friend, a comforter and tell you how this unfortunate birth had happened to others as well and give you positive factors about what would

improve the situation like the treatment that can take place".

"I am sure even though I would continue to cry helplessly, it would calm me and help me face this life-long challenge. But I found that the doctors treated me like somebody who didn't exist; they just took hold of my baby and a group of specialists, completely ignoring my presence, started talking about my child and how she was surely brain-damaged. Then they turned to me, gave me back my screaming child and bluntly told me that there was something wrong. "She is a spastic", said the doctor, quite pleased at his diagnosis. I can recall how hopelessly upset I was - and how completely bewildered, because I didn't really know what this meant, nor what it would be like after five years.

If this situation is not handled properly, it can have a devastating effect on the family. Parents can lose their faith in professional people and can get thoroughly disillusioned.

A Carnegie Report states that "the parents' worry, frustration and uncertainty in dealing with the handicapped child found expression in the form of resentment against medical authorities."

One can venture to say that the understanding of the handicap and the relationship with medical authorities

are intimately connected with how the parents are going to accept their child's disability. I tend to agree with Dr. Wigglesworth that the birth of a spastic should be treated as an emergency. The attitude and emotional reactions of the parents are of crucial importance in planning for his effective treatment. It is the doctor's concern over what has happened and the constructive advice he offers that is going to sustain the parent through a period of helpless grief.

DAILY ASPECTS OF LIFE

In the daily aspects of life like feeding, toileting, washing, playing, etc., my study showed that life is in general harder for the handicapped and for those caring for them. We know that the spastic child's lack of head control and lack of sitting balance as well as his insufficient co-ordination makes it difficult for him to feed himself. Further, because of little co-ordination of the lip, tongue and jaw, he also finds it hard to chew and swallow like a normal child. Therefore, he takes longer to feed himself and meal-times are of lengthier period. One mother said "The most trying period during the day is a meal-time. To help them to close their lips, to remind them to chew and then swallow; and not to get upset if they choke and bring out their food, not to reprimand them if a hand involuntarily jerks out and upsets the cup of milk - this is something which

seems to require tremendous patience". In the sphere of sleep, we know that by the age of four, most children tend to sleep undisturbed. According to a Newsom Report about "Four year olds in an Urban Community", eighty percent are said to seldom or never wake. This study showed that nearly all handicapped children woke up at night and needed attention. A mother said, "For four years, we haven't had a complete night's sleep. She would wake up four or five times at night, screaming. We would have to hold her, prop ourselves against the wall and sleep. I used to wonder how my husband could go for work the next morning".

It has been said that a mother, as much as any worker, recuperates during a period of rest, however much she may enjoy her daytime role.

In the area of play, when asked how the children fared, the mother said they needed and demanded attention all the time. Some mothers had built up a regime of fetching and carrying for the child and the child, not being mentally handicapped, capitalised on this. It certainly did not help him to use his own resources to amuse himself. There is a crucial need to guide and educate the mother, to tell her what correct handling at home is going to achieve and how harmful are the effects of incorrect handling.

SOCIALISATION

In the area of socialisation, these children hardly come into contact with normal children of their own age. We know that interaction with one's peers is important, but due to their restricted mobility, they cannot run out and play with others and it was not possible for the mothers to frequently leave their demanding household chores to take their children out to play with others. A mother said: "I think that if the child seldom mixes with normal children from a very young age, the child will find it hard to adjust himself to normal society later and find it equally heartbreaking suddenly to accept his disabilities. But if the child from a small age mixes with his normal peers, he grows up with the knowledge that there are certain things he will not be able to do like the others".

I have noticed myself, that the moment my daughter started playing with normal children, the response was both ways. I was surprised at the concessions the normal children made - how much consideration they showed while playing a game and how soon they were ready to accept each other. **I think that the handicapped should not be isolated so much, but rather integrated.** If I were blind or deaf or handicapped in any way, I don't think I would like being segregated with them continuously. To change

a system overnight is not possible, I know, but parents feel schools and centres should keep in close touch with their community and try to organise some activity during the week, bringing handicapped and normal children together.

I mention the above facts on feeding, sleeping and play only to give an insight into the enormous strain involved in looking after a handicapped child and how his mere presence can disrupt the internal pattern of a family.

Let us now deal with "Help from the Services". Although all six families had come in contact with various professional people, none of them were fully aware of the services available in the country. Except for one family, none knew that a state grant for further education was available. Two families had spent £7 on equipment, to which, they found out later, they were entitled from the National Health Service. England enjoys a remarkable position where so many facilities are available for the handicapped at no extra cost to the family.

Each of the families had been visited by various people from the Health and Welfare Department of The Spastics Society, but none had any regular visiting by one person. They were of the opinion that only regular visits would allow them to get to know a person well enough to talk over their difficulties. Mothers also felt

that they needed practical help during certain moments of stress. I, myself, had just had another baby and I found that the helplessness of my five year old spastic girl could be likened to a baby. Suddenly, I find myself looking after two babies. It was particularly hard during that one time of the day, when both had to be fed. I discovered an ingenious way of holding the bottle with one hand and feeding my daughter with the other. I was sure that I could keep devising methods, but I must confess it was taxing on the nerves. I wished, during these moments, which was, in fact, just two hours in the evening, that there was somebody who could help and disappear afterwards.

I will now turn to the handicapped's relations with the community. By illustrating certain stories, I shall show you how the reaction of the outside world, to the spastic child, can effect the parents.

It is hard to believe how cruel other people can be. One next door neighbour asked a mother, would she please not put her handicapped child out in the garden, as it was upsetting her children; and it's not uncommon for someone to say outright, "Wouldn't it have been better if the child had died at birth?". I remember the first birthday party to which I took my daughter, Malini. We were both very excited and dressed up for the occasion. When we got there, the games were such that she couldn't join in; and

nobody called her to join in, either. After a while, the hostess took around some hats and whistles. She gave to everyone, except my little daughter, probably thinking she wouldn't enjoy them. I found that my girl became very stiff and tense and didn't want to participate at all. She had sensed the atmosphere. For me, too, the excitement was over.

Mothers feel very strongly about people offering advice and making careless comments. They had all had unpleasant experiences. To recall one such experience, a mother said, "At a Christmas party, someone, who didn't know me too well, came up to me and said in a loud voice, "Why don't you put a collar round her neck, so that he won't loll so much?" This made me very conscious of my little boy. I was sure that everybody was staring at him. I was frantic. I mumbled some reply, but all I wanted was to run away and hide". I suppose the support and comfort of friends and relatives is one thing but facing the outside world and the curiosity of casual acquaintances is quite another.

One cannot hope to prevent the whole world from making thoughtless comments; one can, however, attempt to make the parent less sensitive and vulnerable to comments and stronger eventually; to feel less isolated and stigmatised and less withdrawn. How do we hope to achieve this? All parents in this study expressed a desire to meet other families and talk of their difficulties. They felt that this would relieve them

of pent-up emotions. Research is accumulating to show how effective a role parent-bodies can play. During the past fifteen years, there has been a significant increase in the formation of groups of parents of handicapped children in the U.S.A. and Canada. In Canada, three thousand parents were investigated and in fifty percent of the returned questionnaires, an observation had been made on the importance of parent contact. Parent bodies should be formed where parents should meet regularly and be encouraged to talk freely of their difficulties. It is only through such interaction that parents will find the strength to cope with their own problems and to help others in a similar situation.

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