CHAPTER-VII
AN OVERVIEW

During the last few decades there have been major and somewhat dramatic changes in the ways in which handicapped children are cared for. Although scientists have succeeded to some extent in exploring the biochemical and genetical basis of mental and physical handicaps, psycho-social factors which play an important role seem to have been emphasised lesser. The present investigation was carried out to study the psycho-social correlates of families with handicapped children. This study of families with a handicapped child (physically/mentally) and a matched group of families with a normal child offers an opportunity to examine the impact of a handicapped child on the parents' attitude, marital adjustment, and social burden. It also aimed at studying the temperament of the handicapped children.

The handicapped child is not alone in his plight, his illness and his reactions, undoubtedly affect his parents. While interviewing mothers, it was noticed that nearly all the mothers stated that they wanted to know the truth about their child's condition as soon as possible. Surprisingly, they regarded communications about facts unsatisfactory and wanted to confirm it again and again by going to the best doctors, therapists and medical practitioners. Some of the mothers, who were educated, found faults with post medical treatment whereas rest of them blamed their luck, the improper care of their in-laws, nutritional deficiency and their own ignorance. It was found that out of hundred handicapped children, thirteen children were delivered at home by some
nurse or "Daai". Inexperienced hands and lack of facilities can also be assumed as contributing factors in a handicap.

The impact of the child's handicap on the mother and many attendant anxieties and apprehensions were noticed in nearly all the families of handicapped children. The attitude of the mother towards the child seems to have an important impact on the child's psychological make up. Her perception of the whole situation depends largely on her attitude and this affects her interaction with and acceptance of the child. A mother, who has a positive attitude towards the handicapped child, would perceive less of a social burden and would accept the child more easily than the one who has a negative attitude. More the child feels accepted, lesser the psychological problems he would have.

It is significant to note that the attitude of mothers towards the management of handicapped boys was more favourable than their attitude towards the handicapped girls. This is in line with the prevalent sex discrimination in the Indian culture.

In most of the cases, marital instability and dissatisfaction started at the birth of the handicapped child and crisis provoked at the rearing of the handicapped child that finally precipitated marital maladjustment. The present study confirms that the handicap has an adverse effect on marital integration and satisfaction. The mothers of normal children were better adjusted maritally than those of physically handicapped children followed by those of mentally handicapped children. The maximum effect was noticed in the
of the mothers expressed their fears for the next pregnancy after having a handicapped child. Ten percent mothers reported that they never thought of having another child though they had only one child who was handicapped.

In Indian families, mothers engross themselves in the care of their children. In the case of handicapped child, it is all the more so because the whole responsibility of looking after the child falls on them only. Their involvement in the task of caring for the child probably makes them relatively less available to their husbands (physically, socially, and emotionally). This impairs their marital relationships. Marital maladjustment affects the interaction of mothers with the handicapped children and their management. The present findings confirm that the attitude towards the handicap and attitude towards management of handicap are related to the marital adjustment of parents. It was found that more the satisfied and maritally adjusted the mothers were, the more favourable attitude they had towards the handicap, and towards the management of the handicapped.

The results of the study further indicate that the presence of a handicapped child leads to disruption in family routine and family interaction. The disruption was felt more often by the mothers of mentally handicapped children. It was also noticed that the mothers of handicapped girls felt more disruption in family leisure than the mothers of handicapped boys. The mothers did not feel it appropriate to leave the handicapped girls behind while they went for an outing. The results showed that in case of mentally handicapped group
disruption in family interaction was related to the orientation towards child rearing. More the orientation was positive, lesser the disruption in family interaction did the mother report.

In the interviews, mothers of handicapped children reported symptoms of continuous headaches, lethargy, feeling of being run down and also conditions like bronchitis, backache, lack of sleep, etc. Forty percent mothers experienced some symptoms of ill health. In addition, almost all the mothers whether living in a joint family or nuclear family experienced some form of mental ill health in terms of being nervy on the point of being depressed. A low level of parental health affects all the aspects of family life, particularly, the children. The results showed that mothers of mentally handicapped children felt more breakdowns. It was also found that nonworking mothers' mental health was affected more than that of working mothers' who themselves reported that working outside provided them change and help them to accept the challenge.

Presence of psychological strain in most of the mothers was due to their fear concerning their child's future, non ending "shopping around" and financial burden of looking after such a child. Surprisingly, though the additional expenditure sustained by the families due to the handicap of the child upset the family budgets yet they were ready to spend in excess in case the child could be cured.

It was further noticed that having a handicapped child in the family inevitably posed some practical problems for parents. Domestic chores were interrupted or postponed in
order to provide time for treatment of child. Visits to outpatient clinics may interfere with parents work routines, and, on a long term basis, prove costly and disruptive. Feeding and clothing a child with special needs can prove difficult for those with limited resources. Inspite of all this, mothers willingly shoulder the burden of caring for a handicap child at the cost of their own comforts and leisures. Generally, the mothers acknowledged the existence of hardship but did not resent it. For instance, one mother commented, "Sometimes I get tired, but I would like to look after him and take care of all his needs myself". Similarly, another mother commented, "The child is created from my own blood, from my own body, so I cannot leave him on his own when he needs me. I still love him". When the mothers were asked the straight forward question regarding the burden of such children, about 50% mothers of physically handicapped children and 48% mothers of mentally handicapped children reported moderate degree of burden; 46% mothers of mentally handicapped children perceived severe burden, whereas it was only 16% in the case of physically handicapped group; 6% mothers of mentally handicapped and 28% mothers of physically handicapped perceived no burden. It was observed that most of the mothers reported that they had less spare time and less fun in life because of the child's handicap. One of the mothers described it this way: "Whenever I go out leaving him behind, he is always in my mind. I keep on thinking that he will be hungry, he will be feeling cold or whether somebody helped him in toileting or not".

Emotional disturbance is reflected in children's
temperament and behaviour as well. The results on sociability, emotionality, energy, and distractability (temperament characteristics) showed that normal children were higher on all these characteristics as compared to handicapped children. In the handicapped groups, physically handicapped children were found to be more sociable and distractable than the mentally handicapped children. The difference in emotionality was in the reverse direction, i.e., mentally handicapped children were more emotional than the physically handicapped ones. On energy, the children of the two-handicapped groups did not show any difference. The sex difference was most prominent in the temperamental characteristics. Boys were more energetic than girls in both the handicapped groups. The handicapped boys in both groups were more sociable and more distractable than their female counterparts. However, the trend was opposite in the normal group, i.e., girls were more sociable and distractable than boys. The findings further showed that the more energetic or more emotional the child is, the more disrupted the family leisure or physical health of the mother will be.

The sociability characteristic of mentally handicapped children had negative correlation with effect on mental health of the mothers, i.e., more sociable the mentally handicapped child, the lesser the effect on mental health of the mothers.

To sum up, one can conclude that impact of the handicap on parental attitudes, social burden, and children's temperament would depend upon the type of the handicap and sex of the
Families of the mentally handicapped children seem to be affected more than those of the physically handicapped. With regard to sex, the mothers of the handicapped girls have less favourable attitude towards management of the handicap and feel more disrupted than those of the handicapped boys.