CHAPTER VIII
IMPLICATIONS, LIMITATIONS, AND SUGGESTIONS FOR FUTURE RESEARCH

Implications

The present study was an attempt to explore the impact of the handicapped child on the family. Parents of the handicapped children who present themselves at Rehabilitation Centres or hospitals are not just medical or surgical entities; they have an affected or diseased child that needs special care. They are persons with a wide variety of physical, emotional, social and spiritual needs and aspirations. The moment they are aware that they have a handicapped child (physically or mentally), a lot of problems (conscious and unconscious) start to surface. These parents and their children have to be dealt with differently than the other patients and their relatives.

The present results have some implications for pediatric management. Prominent in the interviews were the marked loneliness and anxieties reported by many of the mothers. They often had intense concerns about their child's appearance that affected their physical and mental health. However, the children generally appeared much less affected and more normal than the parents' impressions of their condition. For this reason, in most instances, the child's problems should be discussed with the family in a way that would emphasize the child's normal attributes; this would serve to minimize parents' social burden and awesome sense of child's abnormality. The long term care of handicapped children may be improved considerably by the pediatricians and social
workers' interventions. Their availability to the family helps throughout the child's development and places them in a unique position to aid the family's adaptation to the child's handicap. Not only this, the knowledge of handicap may help parents to adopt positive attitude towards the handicap and management of their child. The parents should be made to realise the importance of the child rearing techniques as are essential for the healthy development of a child's personality and temperament.

From the study of temperamental characteristics, it is observed that handicapped children are more reserved, withdrawn, shy, emotionally vulnerable and less energetic compared to the normal children. To get them out of this trend, they may need short term psychotherapeutic interventions. The therapist's knowledge of these characteristics would facilitate the treatment as well as rehabilitation programmes. It should always be kept in mind that these children should be treated differently from normal children as they are children with special needs and want more care and support emotionally. They are the ones who may suffer the most. The treating medical team could be forwarded about these characteristics and the consequent reactions which would help them not to react negatively towards such children.

Assessing the temperamental characteristics have also some significance in assigning patients with similar characteristics for group counselling. The members of this group may understand each other and may be of support to each other, especially if the handicap is the same.
As regards this, one more important implication is that the positive temperament of handicapped children helps in favourable orientation towards child rearing and health of the parents. The medical personnels involved in such cases can help parents by improving the children's temperament or by guiding parents regarding the significance of positive orientation towards child rearing. The implication can be more helpful while dealing with the nonworking mothers who mostly remain lost in their own world without having any outlet for their anxieties and have no change in their routines. The present results confirmed that the mental health of the nonworking mothers was more affected than those of working mothers.

Of the physically handicapped children, 52% were females. They have special problems like self image, anxiety about marriage and motherhood, etc. It should not be taken for granted that the handicapped girls are not bothered about beauty, complexion, and physical appearance. On the other hand, they are just as much concerned about these things as their normal counterparts. These facts should be kept in mind by those who deal with these children.

Another issue that is important in the case of parents of handicapped children is their marital adjustment. Better marital adjustment would lead to the more positive attitude towards handicap and the management of the handicapped child. Satisfied and integrated relations of parents can provide the favourable response towards the caring and development of handicapped children. In Indian families, where females are at subservient position, women have to suffer a lot due to
the handicap of the child. They are sometimes even blamed by
their husbands and other members of the family for producing
the handicapped child. The social workers and psychiatrists
should consider parental relations as one of the important
issues and should provide marital counselling to the couple
from time to time.

Rehabilitation of a handicapped child encompasses not
only the individual care but also rehabilitation of the
family unit in its totality. Unless one is aware of the
problems faced by the parents and other family members of the
handicapped child as well as those faced by the child
himself, such rehabilitation services can not be provided
satisfactorily. It is, therefore, of utmost importance to
study the different types of problems faced by the family
members in the bringing up of handicapped children, so that
adequate preventive and remedial measures can be taken by the
various personnel concerned in rehabilitation.

At all stages of illness, the families and children have
physical as well as psychological problems accompanied by
social and occupational disabilities. These create a lot of
stress. A "total care" in a comprehensive rehabilitation
includes giving (a) the best scientific medical treatment (b)
attention to the families where social and familial
relationships and parents marital adjustment had been
disrupted by their child's handicap (c) providing a way to
meet the financial needs caused by the expensive medical
treatment (d) spiritual help through which both the
handicapped children and their families find strength and
hope in God and religion, when hope is lost under the impact
of disease/handicap (e) information alongwith the sessions on early detection procedures about psychological and social consequences of handicap and how to handle them effectively.

In India, unfortunately, we have not been able to accord priority to the handicapped though it is a significant public health problem. Diagnostic and therapeutic facilities are restricted to a few cities. The services available for such children are not very satisfactory in other fields too, i.e., educational, vocational, residential, employment, etc. Services for the handicapped are practically non-existent compared to the need. A combined effort by psychiatrists, psychologists, psychiatric social workers and other health care personnel would be a tremendous support in the rehabilitation programmes for the handicapped.

Transcultural Implications

Attitudes towards physical or mental handicap in India are to be understood in its socioeconomic, philosphical, and religious background. Majority of the subjects studied belonged to the two major religious groups—Hindus and Sikhs. Sikhism is an offshoot of Hinduism. Both the groups have certain common socio-cultural and religious attitudes, values, and ideologies. To understand the social and psychological world of Indian handicapped children, it is to be taken into account as to how the children and families accept the handicap, how they behave in a particular manner under stress, and how these influence the children’s temperament.

In Indian culture, sons are more wanted than the daughters because daughters have to go to their husbands'
homes after their marriages and parents are supposed to live with their sons, not with daughters, if need be. Sons are considered to carry the name of the family by expanding their own family and they look after the parents in old age. All this makes the Indian parents give more attention to sons than to daughters. One should keep these things in mind while handling such families.

One of the religious philosophies on suffering both for Hindus and Sikhs is based on the law of "Karma" which is an ineluctable necessity, a kind of cosmic mechanism from which there is no escape. The present existence is shaped and determined by the deeds (Karma) of a previous existence. Man is caught up in this stream of rebirth cycle. He just cannot help it. So all the sufferings are to past deeds or these are the punishment of the bad "Karamas". This philosophy has a bearing on the parents of the handicapped children and they even tend to train their children with this view. Such fatalistic attitudes and law of retribution make them feel guilty, so they accept the handicaps by considering it as a punishment. The families with handicapped children studied also indicated a sense of helplessness. The sufferings were considered to be ordained by gods; they were thought to be the result of misfortune.

Besides other duties, which the medical team perform in all the countries for the treatment and rehabilitation of the handicapped, the Indian medical personnel have to keep in mind the ideologies and misconceptions of Indian parents. These issues need special attention by the psychiatric social workers and the other members of the medical team in the
Indian context. It is essential that those dealings with such parent are able to relieve them of their guilt feelings by explaining to them the truths about the child's illness.

The caring for the handicapped child would imply understanding of the Indian value system, beliefs and philosophy. The families and children react within this system. Applying a therapy based on some Western philosophy may not be very appropriate in the Indian context. The therapy systems could be adapted to the Indian situation in order to help these families.

Limitations and Suggestions for a Future Research:

Socio-Psychological factors of families with handicapped children entail a vast area. To study all the aspects of such families was beyond the scope of this study. Certain aspects of social and psychological correlates were studied in the present investigation. Some of the limitations which have been observed are listed below.

1) The sample was relatively small and not very heterogeneous, which means the generalisations should be made with caution. The sample has been taken from Chandigarh and nearby areas of the state which has its own culture, so there is clearly the need for such a study on another sample of the families with handicapped children of other places too.

2) For the physically handicapped group, only orthopaedically handicapped children were selected in mentally handicapped group, a limited range of I.Q (I.Q.35-70) was taken for the purpose of this study. The future work may need to extend this
categorisation. The severity and kind of handicap may also be taken into consideration.

3) The age range of the children was also restricted from 8 years to 15 years. It would be fruitful to conduct another study to assess the social burden of young infants on parents.

4) The study aimed at understanding the "Total Impact". However, only a part of the psychological and social parameters has been tapped. There is still another area, viz; "Spiritual" which needs to be studied. India being a country of great cultural and deep spiritual traditions, it is important to study this aspect also in the families of the handicapped children.

5) Only mothers have included in the present study. It would be useful if fathers too could be contacted and interviewed to get additional information on all the variables.

6) Other variables like birth order of the child, place of residence, parents' age, and their education need to be studied in relation to the variables undertaken in the present investigation.