CHAPTER I
INTRODUCTION

In every age, men have recognised the special importance of the child's role in society. Whether through ancient tribal initiation rituals or the pronouncements of contemporary psychoanalytic theorists, each succeeding civilisation has acknowledged that the child will carry after us the imprint of the world we create around him. Paradoxically, however, the child has been a traditional victim of our neglect and abuse. An inability and unwillingness to respond to the special needs of the child haunts us. Tonight thousands of children will fall into troubled sleep, bearing the scars of emotional trauma and physically pain inflicted by adults. We have not yet matched our best instincts and insights with comparable action and nowhere is this more apparent than in the field of mental health (Gattozzi et al., 1975).

With the better control of infectious diseases of childhood and with the improved neonatal care for infants at risk, chronic illness and disabilities are likely to assume greater importance in pediatric care. It is true not only because of the large number of the children involved but also because of the profound and long lasting effects of a handicap on the child and his family.

With regard to prevalence of handicaps, without including mental deficiency, it is estimated that depending upon strictness of definition 5-20% of children suffer from some
handicap or the other (Pless and Roghmann, 1971). It is estimated that in the world, there are about 500 million handicapped individuals. In fact, these are just the rough estimates and no one really knows how many handicapped children are there in India, or in any other country for that matter. The reasons for this are (i) imprecise definitions of a handicap, (ii) lack of representative population in various studies, and (iii) unreliable methods of registration.

Moreover, the sense of guilt and shame, felt on the birth of the handicapped, makes parents reluctant to give information about them. Due to these reasons, no dependable data are available about the size of the handicapped population.

While recognising the scarcity of the reliable information, WHO collected all the available data on the handicapped and found that 15-20% of the world's children are handicapped in terms of the "Serious obstacles to a child's development" (Noble, 1981). Not unexpectedly, 3/4th of these children are found in the third world and these numbers will grow to 4/5th soon (Ibid).

In India, varying divergent estimates are available. As per 1981 estimates in India, there are 3 to 4 million obviously disabled children of whom 3,00,000 are blind, about 6,00,000 orthopaedically handicapped and 2.5 to 3 million are mentally retarded (based upon the fact that 1% children of school going age are sufficiently retarded, who require special attention).

A study undertaken by the Indian Council of Medical
Research in 1971 estimated that there were about a million orthopaedically handicapped persons in India. The 1981 census had put the figure of totally crippled as 2.76 lakh (excluding Assam). Seventy percent of the orthopaedically handicapped in India live in villages. About 35% of these persons do not need special appliances to lead a fairly normal life. Sarvekshana (1983) reported that there were 12 million physically handicapped persons. It is estimated that 1.5% of children and 4% of adults in India are orthopaedically handicapped (Mehta, 1982). As regards mental retardation, prevalence figures vary a great deal. Prabhu (1975) summerising ten surveys of mental retardation has reported an overall rate of 2.5%.

This means that there are nearly 20 million affected persons. Apart from human considerations, it is a tremendous waste of life and resources. The overwhelming majority (87%) of the mentally retarded fall into mild retardation category and the remaining 13% belong to the moderate, severe and profound categories.

It has been argued for many years that the family is an appropriate unit for health intervention (Litman, 1974; Courant, 1981). The assumptions of a family approach to health care are that the course and outcome of a given illness are influenced by the way family members behave with each other and that the psychosocial context affects individual's adaptation to disease (Goldenberg and Goldenberg, 1980).

Chronic illness is not merely an isolated event in the life of the individual but a situation which profoundly
Disorders which cripple young children are "family" diseases in the sense that they cause emotional and financial disruptions of families (Johnson and Price, 1980). Not only does the family affect child's health but families tend to experience illness as a unit (Craven and Sharp, 1927). From a common cold to a major life threatening illness, other family members are affected to a greater or lesser degree by the symptomatology of the identified patient (Huth, 1978). The family often responds as an organic entity to the stresses of illness in a family member (Chapman, 1980). It has also been pointed out that the family is usually thrown into a state of disequilibrium by stress of illness. The initial psychosocial effects of illness and handicap are almost inevitable family disruption and disorganisation (Goldson, 1981). Stress of illness also accentuates potential problems in family adjustment and social relationships.

After accepting the reality of a handicapped child, the ways in which parents visualise themselves in this particulars role has been studied by Boggs (1961). According to him, to some parents this means primarily a sense that they themselves are biologically imprefect as progenitor. By other couples, it may be interpreted to mean that they have been especially selected as parents of a child who needs more than usual care and affection. In still other parents, the arrival of a handicapped child may arouse and accentuate the most basic paternal and maternal instincts for the preservation and protection of the young. However, there are parents to whom the handicap means mostly a sense of
frustration in carrying out the parental role of nurturance and upbringing of a handicapped child to maturity and independence.


Menalcscino (1960) and Wolfensberger (1967) have suggested that there are three kinds of crisis that are precipitated by the news that their child is handicapped. The first of these is the "Novelty Crisis". All the hopes and dreams of the parents are shattered, and the parents have to begin to rebuild their world in the light of this tragic news. The novelty crisis is short lived. The second type of crisis is a crisis of "Personal Values". In this phase, parents are put in a conflict situation and a good deal of stress can result. The third type of crisis is a "Reality Crisis". This stems from the fact that there are a number of very concrete concerns that face the parents of a handicapped child, e.g., financial worries, medical problems, and problems of extra time and care.

Farber (1955) conceptualised the reaction of families of the handicapped in the following five stages:

(i) Attempts to handle deviance within existing family arrangements: In this stage, the family tries to ignore the fact that something has occurred which is not in keeping with the normal course of events. (ii) Distortions of family coalitions as a basis for defining the problems: The family members define their problems in terms of the ways in which
the family relationships are changed. (iii) Revision of age and sex roles: There is a revision of responsibility within the family. (iv) Revision of coalition with extra family individuals and groups: As the crisis situation deepens the family members may become highly selective in maintaining relationships with friends or relatives of they may stop all outside activities. (v) The elimination of deviant members—Institutionalisation, if the rearrangement of the roles within the family and in relation to the community are not satisfactory.

Kohut (1966) described the impact of an abnormal child as crisis situation. The family's ability to adapt to the situation was considered in three stages, i.e., Initial disorganisation, Reintegration, and Mature adaptation.

Drotar et al. (1975) hypothesized a model of a normal sequence of parental reactions during the process of adjustment to congenital disability. The first phase is the "Shock Phase" characterised by a "paralysis of action, confusion, and unrealistic feeling". This is followed by the "Denial Phase". The most common reaction in this phase is not acknowledging the child's retardation and explaining it on the basis of stubbornness, slow learning, etc. Next is the phase of "Sadness, Anger, and Anxiety". The anger may be directed towards the child, self, or the clinician who has given the diagnosis. This is followed by the "Phase of Adaptation". This is the phase of recovery. The parents recover from the acute pain and begin to move towards the problem in a more realistic manner. The last phase is termed the "Phase of Reorganisations". It results in accomplishing
plans and goals for successfully overcoming obstacles created by the retardation.

Quine and Pahl (1987) found no evidence of neurotic patterns of responses such as guilt, rejection, over protection or non acceptance which many earlier writers have reported (Grebler, 1952; Schonell, 1957; Forrer, 1959; Roos, 1963; Schaffer, 1964). The majority of parents' responses appeared to be adaptive rather than dysfunctional. At first, they were deeply shocked, but these feelings were followed by a process of reorganisation and adaptation as they began to think how best they could help their child to integrate his/her life. These stages were similar to those following bereavement (Shapiro, 1983).

Several studies have viewed it as a crisis producing grief followed by stages of shock and disbelief, denial, anger, adaptation and adjustment similar to the phases indentified in bereavement literature (Kennedy, 1970; Emde and Brown, 1978; Cunningham, 1979). Reference is also made to chronic sorrow (Olanshansky, 1962). A large number of studies report on identification of Down's Syndrome (Drillien and Wilkinson, 1964; Berg et al., 1969; Carr, 1970; Pueschel and Murphy, 1976; Cunningham and Sloper 1977; Lucas and Lucas, 1980), Spina bifida (Hare, 1966; D'Acry 1968; Fost, 1981) or severe mental handicap (Hewett,1972; Smith and Philips, 1978; Pahl and Quine, 1984; Quine and Pahl,1986).

Arya (1970) has also stated that the diagnosis of retardation gives a shock to the child's parents. The birth of such a child precipitates family crisis. There is usually a lack of communication with professional people from
the parents of such children who are generally misinformed. Such a child has frequently less contact with his parents and peers resulting in understimulation. The parents' overattention or negligence may increase the level of retardation. Sincere efforts on the part of parents should help the retarded.

Ann Gath (1977) interviewed 52 parents of handicapped children, and reported that the majority of the parents felt the birth of an abnormal child to be a severe blow to their self esteem and this was most evident when the affected child was the first born. He found that the mothers of such children had problems of depression, mood lability, and feeling of being tired all the time.

Ranade (1977) and Pillai (1979) have suggested that the parents of handicapped children are unable to accept the fact and the knowledge and understanding of the handicap.

Farbrega and Haka' (1967) noted in their study of 47 families of handicapped children that those who showed unresolved grief were found to be depressed and anxious. Many parents feel angry and frustrated with the doctor who made the diagnosis. This is a confusion with the anger and bitterness over what has happened to them (Green, 1981). Personal disaster has been described as a feeling of numbness characterized by a withdrawal from reality (Kew, 1975). Resolution of these feelings is apparently quite variable. Resentment, irritation at the unexpected burden, and anger are possible reactions yielding either punishment, rejection, or ignoring of the ill member (Shapiro and Harris, 1976).
Mothers may develop unrealistically low expectations for their child to protect themselves from disappointment and adopt a custodial rather than parental roles (Strand, 1979; Burden, 1980). Even more common are the feelings of anxiety and uncertainty, often producing over protectiveness and overindulgence towards the child. Anxiety may focus initially on the appearance and/or care of the child and later may be directed to questions of future function and/or survival. Fathers also seem to derive less satisfaction from these children (Cummings, 1970).

Another feeling, that the majority of parents report, is guilt; guilt that they had produced a handicapped child (Boggs, 1961); guilt that they have let down their family (Neff and Weiss, 1965; MC Daniel, 1969; Wright, 1970); guilt that they themselves have caused the handicap in some way (Mackeith, 1973; Gracia, 1979); guilt that they reject the child (Shapiro and Harris, 1976; Strand, 1979); and often wish he or she had not been born or was dead (Gruppo, 1978; Minde, K. Hackett, 1972; Heisler, 1972). These feelings are almost universal. Many parents reported that so many of the fears, which seemed conquerable become unimportant when shared, particularly when shared with somebody who understood and had the relevant information and time to listen (Cunningham and Sloper, 1978).

Parents of affected children often display both psychosomatic and psychiatric illnesses especially depressive disorders (Lawler, T.H., Nakielrey and Wright, 1966). Parents also experience sleep disturbances, nightmares, increase in smoking, anorexia, and a need for tranquilizers.
and sedation (Kanof and Kutner, 1972). They may report themselves to be tired, worried, and generally unwell (Walker, Thomas, and Russell, 1971). Wolberg (1944) suggested that mothers with rejecting attitudes towards their child, are usually immature, unstable, neurotic, or actually psychotic.

Mother's rejection of the child may be a facet of neurosis. Matheny and Vernick (1969) suggested that these parents were not really neurotic but were rather deprived of satisfactory information about their child. Hofstatter and Hofstatter (1970) reported that parents with pre-existing emotional problems may become sensitized by the stress of having a retarded child and may develop behavioural, neurotic, or even psychotic reactions.

It is also common to find parents who accept the child but not the handicap. They go from doctor to doctor seeking a miracle, searching for someone who will say that this is all a mistake (Cunningham and Sloper, 1978). There are times when the handicap produces tremendous strain on the family. There are some children who become so unmanageable as they grow older that daily life for all concerned becomes intolerable. The frequently reported phenomenon of chronic sorrow (Gruppo, 1978) refers to parental emotional response to their child's handicap where, become the child does not die, parents must deal with issues of loss and disappointment on an ongoing often unresolved basis. Burden (1980) reported that higher levels of depression and anxiety exist in mothers of handicapped children than in the general population. The more able child is to care for him or herself lesser the strain on the family, even then, the reaction of other
people, particularly family and friends, can give rise to feelings of embarrassment and shame. Many parents are acutely embarrassed and ashamed of the child's handicap and seek to avoid situations where the child's differences are accentuated or commented upon. Hospitals, Doctors' waiting rooms, baby clinics and even shopping trips become an ordeal of embarrassment for the sensitive parents.

Prabhu (1970) studied the personality characteristics of the parents who overestimated the potentialities of their handicapped children and those who evaluated them appropriately.

The results showed that the parents who overestimated were more extrovert, emotionally unstable, and had a poor self concept.

Rastogi (1981) observed that mothers showed more negative attitudes towards their handicapped child as compared to fathers and both the parents of severely retarded children had more negative attitudes as compared to the parents of mildly retarded children.

Not only parents but sibling relationships also are affected by the presence of the handicapped child. Shere (1956) studied the parent child relationships of 30 pairs of twins, one of whom in each pair had cerebral palsy. She found differences in parental behaviours which she thought contributed to the non-handicapped twin's view of being unfairly treated in comparison to the handicapped sibling.

Farber (1960) interviewed the siblings of severely
Two significant sibling relationship effects emerged. Siblings younger than the retarded child assumed a superordinate role and female siblings were frequently encouraged to function as surrogate mothers for the retarded child. Meuwissen (1971) has suggested that guilt may inhibit expression of negative feelings towards the handicapped sibling. However, in Miller's study (1974) children indicated that their parents did not tolerate the expression of negative affect towards the retarded sibling.

The needs and adjustment of siblings of handicapped have been largely neglected. Tew and Laurence (1973) found that the sibling of mildly and severely handicapped children were more likely to manifest psychological disturbance in school than were the siblings of non-handicapped control children. Reports of mothers of physically handicapped children indicate that a significant group of non-handicapped siblings may be disadvantaged by the presence of the handicapped children. Kendell and Calmann (1964) reported that siblings suffered emotional deprivation in 38% of the families where as Richards and Mc Intosh (1973) and Mc Andrew (1976) have reported this to be in 22% and 25% respectively. Disturbances reported in these studies are like excessive attention seeking behaviour, head banging, encopresis, school absence, etc. Richardson et al. (1964) opined that the burdens of physical handicap on the family led to a split of the mother and the handicapped from the father and siblings. Pfouts (1976) found that when two brothers in the same family differed significantly in personality assets or intellectual
asset, the boy who suffered from the comparison felt hostility towards the brother outshone him, whereas the adequate brother felt ambivalent rather than hostile towards the less able sibling.

According to Joan Bicknell (1983), siblings within a family with a mentally handicapped member very broadly reflect the parental reaction, but they have problems unique to themselves (Kew, 1975). The most vulnerable sibling is the one next in birth order, either younger or older, than the handicapped person. They are likely to develop symptoms of maladjustment, if their own infantile needs to bond and to be cared for, and to be dependent are not met; if there has been a need for them to accelerate their own process of growing up; if their need to socialise has been stifled; if their school work is interfered with, and, particularly in adolescence, if for the first time their mentally handicapped sibling is an embarrassment to them. Siblings can also become increasingly disquieted when there are anxieties about continuing care of the handicapped person and there is an implicit assumption in the family group that they will carry on the work of their parents. Finally, they will require much help and reassurance concerning their capacity to procreate a healthy subsequent generation.

Besides the effect on sibling relationships, there also appear to be detrimental effects on the non-retarded sibling's (primarily female) individual functioning involving high degrees of anxiety and conflicts with parents, lower sociability, or emphasis on interpersonal relationships and the adoption of life goals involving dedication and
It is clear that an undeniable relationship exists between family and illness and that a specific illness affects and is affected by the family context. In this regard, the factors like income, attitude, marital adjustment, and institutionalisation are of importance.

Farber (1960, 1968, 1970) indicated that parents who kept their children at home showed greater socioeconomic status decline than those parents who institutionalised their children. However, this difference may somewhat be misleading as Gath (1972) reported that wealthier families were more apt to institutionalise their retarded child than were lower income families. Mothers of handicapped children were also more likely to work only part time rather than full time (Watson and Midlarsky, 1979) and to have greater difficulty in arranging child care (Sells et al., 1974; Watson and Midlarsky, 1979).

The relationship and influences between handicapped children and their families would seem to be reciprocal and circular. Victoria Shennan (1981) mentioned that a mentally handicapped young child is no less affected emotionally and damaged psychologically by separation from parents in sickness, simply because he appears less able to communicate his distress. He may, in fact, suffers more since he comprehends less. Handicapped children also experience the reactions of their family and suffer with deeply shocking event. Gattozzi et al. (1975) have rightly pointed out that the mental health of our child rests ultimately on the health of our total society from the smallest unit to the largest,
the stability of the home, the comparison of the surrounding community, the social conscience, and social action. All of these are crucial. So, we should expand the efforts to improve the mental health of children and thus enhance the quality of their lives and our own.

The handicapped remain the responsibility of our society, more specifically, of the family and parents. The adjustment to the reality of a handicapped child would be affected by a number of factors including the nature and extent of the handicap, the way and the time at which the parents are told about the handicap of the child, their reactions, the family's socioeconomic status, the degree of help and support they receive from family, friends, and siblings, and the effect of the handicapped child on other members of the family.

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

Very little work on the problems arising from the presence of a handicapped child in family has been reported...
from India. The present investigation entitled, "A Study of Social and Psychological Factors in Families with Handicapped Children" is an attempt to study the social burden felt by parents, marital adjustment and attitudes of the parents, and temperament of the handicapped (physically/mentally) children in comparison to the normal children. It is hoped that this study would be informative to the professionals involved in the care of handicapped children, in providing an understanding of the atmosphere created by the presence of a handicapped child in a family.

Aims and Objectives:
The present research aims to study

a) the attitudes of the parents of handicapped children,

b) the effect of the handicap of the child on the marital adjustment of the parents,

c) the burden (social) felt by the family of the handicapped children, and

d) the temperament of the handicapped children.