

CHAPTER 1

INTRODUCTION

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Mental retardation and the problems associated with it, have been of great concern to all those related to it since time immemorial. Most of the problems of the mentally retarded is due, not directly to their intellectual defect but to their inability to adjust to the demands made on them by the society. Failure to live up to these expectations leads to an atmosphere of frustration and rejection in the home which makes for a serious social maladjustment. It is the family, therefore, that needs the utmost help in learning to accept the mentally retarded child. Consequently, many studies and research has been done on this subject which has led to a remarkable change in the approaches and method of tackling this problem effectively. With increased knowledge, higher education and fellow feeling, the attitude of the society towards the mentally retarded has gradually changed in the positive direction.

1.1 THE NATURE AND PREVALENCE OF MENTAL RETARDATION

The terms that are often used to refer mental retardation are "mental deficiency", "mental subnormality" "feeble mindedness", "mentally handicapped" "insane" and "idiotic". The definitions of mental retardation that has been evolved through the years has reflected the views and attitudes of society, as well as the diagnostic techniques and the state of medical knowledge.

According to the 1983 American Association of Mental Deficiency (AAMD), mental retardation refers to "significantly subaverage general intellectual functioning existing

concurrently with deficits in adaptive behaviour, and manifested during the developmental period" (H. Grossman, 1983,P.11)¹.

Mental retardation has merely been considered as a symptom that may result from a variety of physically and socially based disorders all of which manifest themselves in reduced intellectual functioning and hampered abilities to adopt to the requirements of everyday life. (Robinson and Robinson, 1976)².

The prevalence of mental retardation at any one time is estimated to be about one percent of the world's population. It is difficult to calculate the incidence of mental retardation accurately because of the impossibility of stating when an individual is diagnosed as being mentally retarded. Interestingly, mental retardation is one and a half times more common amongst males than females. (D. S. M III - R American Psychiatric Association,1987) ³.

According to a survey conducted in 1988 by the National Institute for the Mentally Handicapped, out of the 20 million mentally retarded people in India only a small percentage has been institutionalised or taken care of. There are about 365 schools in which around 3,700 workers are involved. However the present ratio of students and teachers is 12:1 while government recommendations are 5:1. Therefore, it can be inferred that, the burden of providing emotional, social and economic support to the mentally retarded falls largely on their own families and relatives (T.Madhavan et.al 1988)⁴.

In 1981, which was recognised as the International Year of the Disabled, it has been

indicated that nearly 3 percent of the Indian population are mentally retarded. It has been further estimated that about 70 per cent of the mentally retarded are based in the rural areas where no help is provided. In India the ratio between the male and female mentally retarded is 2:1. The majority of the retarded population consists of children. (Girishbala Mohanty 1991)⁵. One of the reasons for the majority of mentally retarded being children could be because of the increasing awareness amongst parents over the last decade. These children are usually brought to the hospitals for diagnosis and sent to specialised schools which ultimately comes on record.

The degrees of levels of mental retardation are expressed in various terms. D.S.M.-III-R classifies four sub types of mental retardation, reflecting the degree of intellectual impairment such as mild mental retardation, moderate mental retardation, severe mental retardation and profound mental retardation. The degree of mental retardation by I. Q. range are indicated in Table 1 (D.S.M. III-R American Psychiatric Association, 1987)³.

TABLE-1.1

SEVERITY OF MENTAL RETARDATION BY I.Q. RANGE

Severity of Mental Retardation	I.Q Range	Percentage of retarded Population
MILD	50-55 TO approx. 70	85
MODERATE	35-40 TO 50-55	10
SEVERE	20-25 TO 35-40	3-4
PROFOUND	Below 20 or 25	1-2

1.2 CAUSES OF MENTAL RETARDATION

Based on current knowledge, three sets of etiological factors are involved either singly or in combination to cause mental retardation. They are genetic factors, environmental biological factors like malnutrition and early childhood- rearing experiences.

Chromosomal and metabolic disorders such as Down's Syndrome (Mongolism) and phenylketonuria (PKU) are the most common disorders manifested in mental retardation. Maternal infections during pregnancy that have been identified as high risk conditions for mental retardation are Rubella (German Measles) and Syphilis. Currently, Acquired Immuno Deficiency Syndrome (AIDS) has become an important area of research and study. This is because the virus is known to affect the brain tissue directly, due to which it is presumed that children born to mothers who are confirmed cases of AIDS may show signs of brain damage with varying degrees of mental retardation.

A prospective mother who is malnourished and lacks antenatal care due to poverty can give birth to a retarded child. During childhood if the child is infected with Encephalitis or Meningitis, it can seriously affect a child's cognitive development. Besides this, head injury due to forcep delivery or accidents during childhood, can also result in mental retardation including seizures (Coleman James. C. 1984)⁶.

It is a well known fact that the environmental, socio- cultural influences and early childhood- rearing experiences are considered to be the major factors responsible in causing mild retardation. Deprivation in social, linguistic and intellectual stimulation has been suspected as contributing to mental retardation. In most of the cases, children from poor,

socio-culturally deprived families are subjected to potentially pathogenic and developmentally adverse conditions. Moreover, the instability in the family, frequent moves and inadequate care takers during childhood can also be precipitating factors for mental retardation (Irving B.Weiner, 1982)⁷.

1.3 MENTAL RETARDATION AND ITS IMPACT ON FAMILY

The presence of a mentally retarded child in the family has a severe impact on the general family atmosphere. The stress and strain associated with handling such children has a direct and disruptive effect on the mental health and attitude of the family members. Thus any problem with one of the members affects the family as a whole. From ancient time, people were having many erroneous beliefs, attitudes and misconception about mental retardation. Before this century, families never used to let the outside world know that they had a mentally retarded person in the family. They believed that such persons were possessed with evil spirits and even harassed them physically.

The attitude reflected by the family members are multi- faceted ranging from resentment to acceptance. The stigma attached to mental retardation leads to social isolation which results in frustration or depression amongst family members. On the other hand, over sympathy from parents hampers the child's training while some parents learn to accept the reality and cope up by being actively involved in their ward's training programme.

1.4 ROLE OF SOCIAL WORK

The concept of the family's attitude has undergone a sea-change over the past hundred years. Therefore, the field of mental retardation is always a premise for professional social

workers to contribute in its treatment and rehabilitation. Since there is no cure for mental retardation, the need for training and rehabilitation assumes importance and the role of a social worker is indispensable in such an approach.

Keeping in view of the above, little emphasis has been made to find out the effectiveness of social case work or social group work counselling in changing the knowledge and attitude of the family towards the mentally retarded in the positive direction. This finally helps in the better management of the mentally retarded child in the family set up.

Over the last decade, many changes have taken place with regard to the training and education of these people. The first school for mentally retarded was started in India during 1941 at Bombay. Ever since 1981 was declared as the "International Year of the Handicapped", there has been a big spurt in the field of mental retardation. The National Institute for the Mentally Handicapped (NIMH) was started in 1986 at Secundrabad with regional offices at Bombay, Calcutta and Delhi.

On screening through the literature in the area of mental retardation, one is struck with the fact that very little mention was made on parental knowledge, attitudes and efficacy of counselling towards management of the mentally retarded as family care approach. Since the family is the primary unit for any child's all round development, the families of the mentally retarded children should be specially trained to accept their vital roles as the child's father, mother, sibling(s) or relative(s).

The present study is mainly intended to cast light on how the families in a semi-urbanised city like Kolhapur, views the presence of a mentally retarded child amongst them. The study will also try to explore ways by which effective and efficient training and rehabilitation programmes can be developed.

1.5 REVIEW OF LITERATURE

There are a number of studies that has been conducted regarding the attitude of the family towards the mentally retarded child in the past. This review of literature was carried out to examine the studies related to the purpose of study and to identify how far the attitudes differ based on the socio-demographic background, educational status of parents, sex of the retarded child and the normal siblings interactional process in the family. Family is based on the bonds between the parents and the child which develops a sense of security, belongingness and love. The attitude of the parents differs from parents to parents towards their mentally retarded child. The birth of a healthy normal child brings much joy to the family and the birth of a mentally handicapped child shatters their dreams and the process of bringing up this child creates problems and this is hazardous to the family.

In general the family is found to be negative towards the severely mentally retarded children and the focus shifting to the acceptance of mild retarded children in the social commune(H.S. Narayan 1979)⁸.

Ehlers, Krischief and Prothero (1977)⁹ states that

"All the parents show either one of the three responses towards the retarded child".

1. They accept the child as he is, what he is and try to recognise its limitations and provide

them the highest possible wholesome environment to achieve the highest possible level.

2. Either they accept or reject, they try to institutionalize the child.
3. They reject the child either part or whole.

Worchel and Worchel (1963)¹⁰ assessed the acceptance and rejection patterns of parents of the mentally retarded children. Most of the parents had negative attitude, since they considered that the mentally retarded child as a taint on the family and doubted about the heredity factors.

Tizard and Grad (1961)¹¹ conducted a survey and made a comparative study of 150 families whose mentally retarded children were institutionalized and 10 families having a retarded child at home. There was disturbed family functioning, curtailment of social contact in 15 percent and one third of the mothers had health problems, in those families who had a retarded at home.

C.K.Rastogi (1981)¹² investigated 50 parents of the mentally retarded children for their attitude. Most of the parents showed a favourable attitude although it was frequently accompanied with feelings of guilt, pessimism and sometimes even hostility and aggression.

Neeradha Chandra Mohan (1989)¹³ studied a group of 60 mentally retarded children with mild, moderate and severe retardation. On examining their mother's attitude towards their children, it was reported that there was no significant differences in the sex of the child. Majority of the mothers were permissive, over protective and optimistic. A small section of mothers exhibited guilt, shame and aggression towards their mentally retarded children.

Suma Narayan's (1993)¹⁴ attempt of the comparison of the perception of the overall impact between the fathers and the mothers showed that only in 3.5 percent of the families out of 69 families, both parents perceived the overall impact as negative. In 74.5 percent of the families both parents saw the overall impact as neutral. In the remaining 22 percent of the families, parents differed in their perception of overall impact.

Grossman (1972)¹⁵ did an exploratory study on the brothers and sisters of mentally retarded which revealed that the presence of a the mentally handicapped child affects the normal development of other siblings.

According to a study conducted by Animasen and Kusum Tule (1991)¹⁶ on the agony of the parents of the mentatilly handicapped, parents reported that due to the handicap of one child, their other children suffered a lot. They couldn't divide their time and attention equitably amongst all their children and mostly the other children are neglected. Another critical problem was that the sisters of marraigable age of these children found it difficult to get proposals since most of people felt that the girl may also develop similar problems. Nearly 93.3 percent of the parents also reported about the adjustment problems between the siblings and the mentally retarded child.

Eveline. M. Sequeira et. al. (1990)¹⁷ studied a group of 55 mothers to assess the extent of the burden perceived and coping styles used in relation to the sex and degree of retardation in their handicapped child. The findings drew attention to the fact that it is

necessary that the family as a whole is strengthened to take care of their handicapped child at home. Long term support should be given to the family by way of parental counselling to accept and utilize more problem focussed coping styles and organisation of self-help groups of parents.

The professional can help the family to cope up with the crisis by finding out the resources of the family, role structure, emotional stability and previous experiences of stress. The strengths of the family can be effectively used to deal with the stressful situation. Girimaji et .al (1990) ¹⁸ states that parental counselling has an essential integration in the overall care of the mentally retarded person, their family from the perspectives of the family care approach.

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