CHAPTER 2

METHODOLOGY

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The problems related to mental retardation has received greater attention in the society only in the present decade. This problem has many physical, psychological and social implications. Since the attitude towards the mentally retarded in the society at large is one of indifference it has become indispensable for social workers to enable atleast the families of mentally retarded to have a right perception. Thus it can be said that if help had been available to the family when attitudes were being formed, the current problems might not have developed.

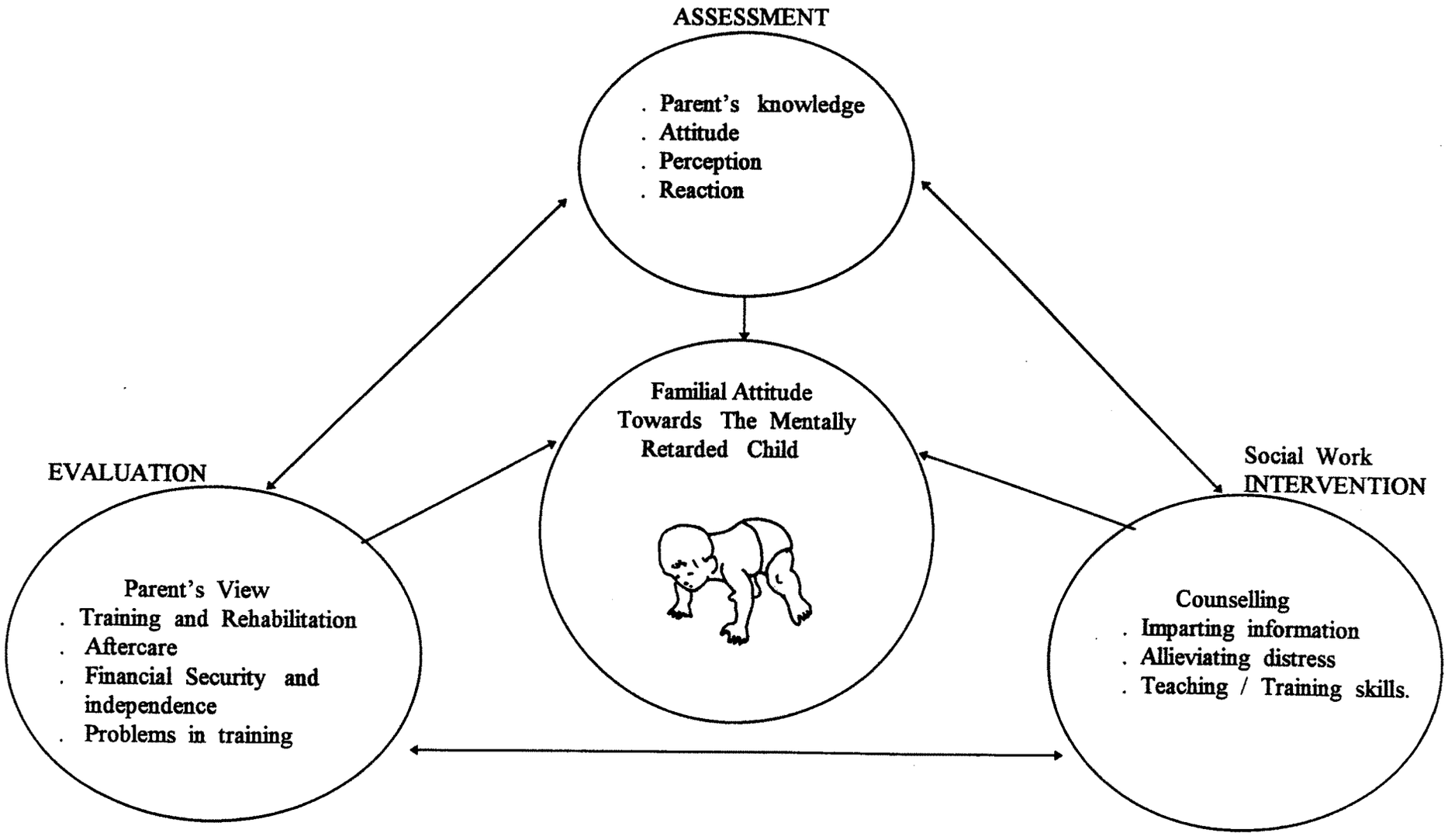
There is a dire need for well designed research on families and their attitude towards mental retardation in our cultural setting. These findings are bound to be relevant in terms of their diagnosis, training and rehabilitation.

The anticipated birth of a child marks an important stage in the life cycle of a family. In the Indian society, in particular, great expectations accompany the imminent arrival of a child. With the birth of a mentally retarded child, the anticipated joyful occassion is characterised by a sense of loss, grief, living nightmare, guilt etc. It is at this juncture that the basic attitudes towards the child is being formed. Parents either tend to over protect the child, deny that the child is mentally retarded, neglect the child or build false hopes about the child's recovery. Consequently, it is only a systematic and detailed understanding of the variety of responses that can enable the therapist to make a more appropriate and efficacious therapeutic intervention.

In India, the institutions offering services for the families of the mentally retarded are very few. The reasons are manifold. Firstly, the families of the mentally retarded are not considered as being directly involved in the treatment or training programme. Secondly, there is dearth of trained professionals to handle the families of mentally retarded in coping with the situation or enabling them to have a right attitude or approach towards training. Thirdly, there is no provision of social security scheme that can be adopted by the families like that which is available in the West.

It is hoped that this study will throw some light on understanding the attitude of families having a mentally retarded child. It would also try to being out suggestions for changing the negative attitudes or intervention techniques which would enhance the quality of life of the mentally retarded.

FIG. 2·1 SCHEMATIC DIAGRAM OF CONCEPTUAL FRAMEWORK OF THE STUDY



2.1 WORKING DEFINITIONS TO BE USED

A) Mental retardation : The researcher wishes to use the term "mental retardation" and the defination given by American Association of Mental Deficiency (1987)1 for this study. According to the D.S.M. III - R classification , the essential features in the definition of mental retardation are

1) significantly subaverage general intellectual function accompanied by
2) significant deficites or impairments in adaptive functioning.
3) with onset before the age of 18.

B) Borderline Retardation : In this study, the researcher has taken children having borderline retardation (I.Q. ranging between 70 to 75) since the schools in Kolhapur has such children. Although this catagory has not been recognised as mentally retarded according to the D.S.M. classification , most of the people consider them to be " slow learners " since they are academically backward and classified as mentally retarded.

C) Attitudes : The researcher has used a number of variables to assess the attitude of the family such as depression, resentment, worry, embarrassment, acceptance, disgusted and over protection.

DEPRESSION :- Depression is found amongst parents who are feeling sad that they have a retarded child. When asked "How do you feel emotionally on seeing your retarded child?" most of them feel like crying or feel guilty on seeing their child.

RESENTMENT :- Some families just want to resent the fact that they have a retarded child at home. They hope that their child will soon return to normalcy and the present state of handicap is just a temporary phase. Thus, they have not come to terms with the reality.

WORRY :- The constant worry amongst parents was assessed by asking "What are the fears you anticipate as your child grows?" or "What have you planned regarding your child's future?" Most of the parents are very anxious regarding this.

EMBARRASSMENT :- Some of the families are embarrassed to admit that they have a retarded child at home especially in front of their well wishers, friends and colleagues since they feel that child's presence would degrade their value and respect.

ACCEPTANCE :- Some of the families accept the retarded child as they are with the passage of time. In relation to the question "Do you take the child for social gatherings?" or "Are you actively involved in the training programme of your child?" the researcher was able to assess how far the families have accepted the child.

DISGUSTED :- It is sad to note that some of families are disgusted and irritated at the presence of the retarded child. Since the retarded child needs constant attention and are entirely dependent on the family members for their daily routines, the family members feel that the retarded children is a real "nuisance".

OVERPROTECTION :- The other extreme attitude seen in families is that of over protection. The parents pamper the child in every respect and refus to let the child strive to

be independent. They feel that the child is incapable of doing anything on its own and may land doing something hazardous. All the demands of the child are catered by such parents if the child is obstinate. They are not even allowed to play outside home for fear of being dehumanized by others.

2.2 AIM

The aim of this study is to understand the families attitude towards the mentally retarded child and its impact on the training and rehabilitation. By comprehending the families attitude, evolve measures which will help effectively in the training process.

2.3 OBJECTIVES

1] To study the level of awareness of parents about the problems of the mentally retarded child.

2] To find out the attitudes of parents and siblings towards the mentally retarded child.

3] To examine the patterns of interaction between the siblings and the retarded child.

4] To evolve new social work strategies for effective training and rehabilitation programmes.

2.4 HYPOTHESES

1] The familial attitude towards the mentally retarded may influence the training.

2] The level of awareness about the problems of mentally retarded amongst parents living in

a semi-urbanized society can be different from an urbanised society.

3] The interactional process between family members can be influenced due to the presence of the mentally retarded child.

4] There may be a relationship between the gender of the child and the care rendered by the parents.

2.5 THE UNIVERSE AND THE SUBJECTS OF THE STUDY

The universe for the study is Kolhapur city. The subjects of the study were the families of mentally retarded children in Kolhapur. These children are studying in three different specialised schools such as:

1] Chetana Vikas Mandir- Shenda Park

2] Swayam Matimand Mulanchi Shala-Kasba Bawada

3] Jignyasa - Mahadwar Road.

After explaining the aims and objectives of the study to all the principals, the researcher sought the permission to collect the addresses of the children studying in these schools. The principals were requested to give a list of names of children whose the training process has been hampered due to the familial attitude in their assessment. A letter introducing the researcher to the parents and encouraging them to give their kind cooperation was also taken from the schools.

2.6 SAMPLING METHOD

The inclusion criteria for the study were :

1] The families who are having children who are above seven years and not exceeding thirty eight years. This is in order to include families who have an understanding of having lived with a mentally retarded person for sometime and the elder siblings have also attained a certain level of maturity.

2] The subjects should be living within 20 km radius of the school. This is to enhance easy accessibility for the researcher to make home-visits.

3] The families should have admitted the mentally retarded child in the school for specialised training before June 1992 so that the researcher can assess the parent's attitudes towards the ongoing training programmes.

4] At least 50 percent of the respondents should have a female mentally retarded child in the family. This is to make a comparative study of attitudes towards the male and female mentally retarded child.

Thus the researcher was able to gather 57 families of mentally retarded children out of the 175 children studying in all the three schools. The children were classified according to their levels of retardation by clinical psychologists with the help of Binet Kamat Intelligence scale and Vineland social Maturity scale.

2.7 RESEARCH DESIGN

A pure experimental research is often not possible in social science research due to

the difficulty in manipulating the variables. This study is meant to describe the family environment, child rearing practices and coping patterns amongst the family members who have a mentally retarded person in their homes. This would help to understand whether the existing findings, mostly drawn from the Western countries and the major cities of India, are applicable to the families in the semi-urban settings like Kolhapur also. Therefore, descriptive diagnostic design has been adopted for this study.

2.8 DATA COLLECTION

The data were collected by the researcher personally from the respondents. The home visits were done for a period of three months from January to March 1994.

2.8.1 Sources Of Data

The data were collected directly from the primary and secondary sources. Families were identified based on the inclusion criteria and their addresses were collected from the child's school register. Clinical reports, level of retardation, date of admission in school and other relevent information were collected from the individual case record files.

For the primary source of information, regarding the families attitude towards the mentally retarded child and the modes of adjustment was collected from the interviewee by visiting their homes or in the school. This includes the factual information and self reported perception in a number of domains concerning the respondent and the retarded.

2.8.2 Research Instruments

The study was completed and the data were collected from the respondents using a

detailed interview schedule that has been appended at the end of this study. The first part of the interview schedule contained questions related to the child and its family members. The second part of the interview schedule dealt with awareness of the family members about mental retardation, problems of family members because of the presence of the mentally retarded child, the family members role and attitude towards training and rehabilitation. Information regarding the interaction between parent child and normal siblings with retarded child were collected during an informal interview using an interview guide and also with the help of a tape recorder.

For measuring attitudes of parents towards their retarded subjects, even though there are certain questionnaires and scales available, none of them has so far been standardized on an Indian population. Therefore an interview schedule was used, as information gathered from it are first hand and reliable. Also it allowed personal contact with the respondent which enabled the researcher to probe deeply into the specific ways of perception caring and training of the respondents.

The tools of the study were translated into Marathi, so as to make the subjects easily grasp the questions.

2.8.3 Method Of Data Collection

Most of the families included in the study was interviewed in their homes except for two families which was interviewed in the school. The aim of the study was individually explained and the consent of each family to participate in the study was obtained. Information about the socio-demographic data, awareness about mental retardation and

psycho-social consequences of having a mentally retarded child were collected. This interview lasted for about two hours in each family.

For each family a date for home-visit was fixed through correspondence. Care was taken to explain to the family members the importance of meeting with the entire family.

Before starting the interview, sufficient time was given to help the family members relax and establish a good rapport. With the prior consent the entire interview was recorded, to enable the researcher to have a detailed information and to have flow in the thinking pattern of the respondents without any kind of interruption. The observation method was adopted in collecting data on the physical appearance of the house and the non verbal interaction amongst the family members and the retarded child.

2.9 PRE-TEST

With the objectives of the study in mind, a screening schedule and a proforma was constructed. Few interviewes were conducted to test the suitability of the research instruments and finalise it. For this purpose seven interviews of the families of mentally retarded was taken.

The pre-test helped to remove questions which did not elicit good response, such as how much money the parents have spent for the retarded child's treatment and training. The pre-test also helped to reframe actual wording and the re-arrangement of questions. Thus the interview schedule to be used for the study was finalised.

2.10 PATTERN OF ANALYSIS

The data obtained were coded and analysed systematically. Simple tables are drawn to give a profile of the respondent. Cross tables are drawn to establish the relationship between social factors affecting or influencing the attitude, perception, reaction, awareness, training, stress and coping patterns of the families. Simple statistical techniques and other measures are used for deeper analysis of the data pertaining to the objectives of the study. The tables contain all the figures in percentages for easier interpretations.

2.11 LIMITATIONS OF THE STUDY

1] This study was conducted only amongst families who sent their mentally retarded child to specialised schools and hence the findings cannot be generalised for all the families who have a mentally retarded child.

2] The size of the sample being rather small the findings of this study must be viewed with caution. The replication of this study on a larger sample would help in the generalisation of the findings.

3] Since the researcher was not fluent in Marathi, one or two responses given by the respondents could not be comprehended to its exactness by the researcher.

2.12 DIFFICULTIES ENCOUNTERED

Most of the parents misunderstood the researcher to be yet another Master of Social work trainee student who wanted the detailed information about the mentally retarded child, due to which they did not show any interest initially. As the rapport was established a lot of

During the period of study there was an uproar in Poona against certain doctors who were performing Hysterectomy operation on young mentally retarded girls. Consequently, many of the parents of female mentally retarded children of this study were in a dilemma and doubt as to what should be their stand and this has indirectly affected the interview.

In atleast five percent of the cases, the families had not given their correct address or notified to the school authorities the change in address. The researcher had to pursue the matter personally and ultimately managed to make the home visits.

REFERENCES

American Psychiatric Association Diagnostic and statistical manual for mental disorders ed. 3, revised. Washington, D.C. American Psychiatric Association. (1987).

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