

CHAPTER I

INTRODUCTION

Background of the study:

Disability refers to certain limitations which incapacitate a person from doing or deprive him or her from the power of acting. The term is conceived differently in ^{Pakistani} society. Some people believe that it is a curse of God and atonement is sought by resort to sacrifices, charity or visit to holy places. Some relate it to their own deficiencies and develop a feeling of guilt which result in the isolation ^{of the} disabled child by hiding him from others. Some have no idea about what is wrong with the child while others perceive it as a form of mental illness.

Disability has far reaching consequences on the lives of the affected individuals as well as the family members. The problems may range from economic and physical hardship to social isolation. The effects are cumulative and may make an already difficult situation, intolerable for the family with a disabled child.

Like all other children, a disabled child is born into a family and remains a life long member of that family. Among all the social institutions, school, community, peers and family, the family is universally regarded as exerting the most significant influence on the child's development as it provides love, care, support, protection, guidance and direction to children. Every family being different from the other provides a wide variety of living arrangements and experiences for the child.

The life of a disabled child is interwoven with that of his family—the parents and the siblings. The way parents and siblings treat a disabled child is a reflection of the attitude they have for disability. These attitudes are the product of child's age, sex, severity of disability and the liability he causes. In the process of attitude formation the parents who reach to the state of passive acceptance actively involve themselves in the education and care of the child, while the parents who do not resolve the initial emotional reactions tend to express negative attitudes towards the child.

The treatment of the child by different family members may also be different. If the message to be communicated to the child from different members of his social gathering are

concordant it will lead to wholesome development of the child but if there are conflicting messages, demands, expectations, help and support, it might develop anxiety in the child and affect his emotional and social development. In Pakistan, with a joint family, most likely having the grand parents, uncles and aunts in the house, the messages to the child are most likely to be conflicting in nature, whereas in a small nuclear family, there is likely to be greater compatibility. A child with a disability may find a positive and rich atmosphere as well as a negative and restricted atmosphere depending on the circumstances present in the family at any particular time.

Parents do not exist in an emotional vacuum. Many pre-existing factors shape their attitude towards the child and the task of rearing. The attitudes of their other children, their own parents, and the extended family members act as important determinants of their behaviour. Besides, background factors existing even prior to the establishment of the family, such as social class membership, religious affiliation and financial status may also mould the way in which they cope with the task of rearing the child.

The present study has been designed, keeping in view the immeasurable importance of these isolating factors which

contribute both positively and negatively to the development of family perceptions, attitude, aspirations and expectations related to the disabled child. Keeping in view the significance of the role of parents and siblings in the life of a disabled child, the study explores the existing problems of families of disabled children. This knowledge of the problems will provide a guideline for developing strategies for working with families with a disabled child.

Statement of the problem:

The study is aimed at studying perceptions of disability, expectations and aspirations about the disabled child and problems faced by the parents and siblings of mentally retarded children residing in Karachi.

Perception of Disability was identified by exploring parents' and siblings' awareness of the child's deficiencies, behavioural manifestation of the disability, cause of disability, presence of disability in other children, identification of child's special needs and need for special schooling for the child.

Identification of parental attitude towards disability

and its impact on the child included parents idea about how people behave towards the child, the child's likes and dislikes, hope for positive change in the child, admission to special school, importance of school meetings, child's presence in social gatherings as well as when friends or guests are around.

For aspirations, the plans for the child's future, educational provisions, occupation, availability of marriage partner, arrangement of marriage, and ability for independent living was explored with the parents and siblings of the disabled children.

Expectations associated with the child inspite of his disability was the next problem under study. It included anticipations related to the child's level of educational achievement, nature of educational achievements, ability to live after marriage, and ability to continue an occupation.

The nature of problems faced by the family of the disabled child involved identification of financial problem, emotional problems, social problems, marital problems as well as the liability caused by the child or the presence of a feeling of guilt or shame.

Significance of the study:

The present study will be useful in many respects as parents are the prime educators and the first to attend to the needs of the disabled child. Besides, siblings also play an important role in the life of a disabled child. The study of the perceptions, expectations and aspirations of parents and siblings of disabled children will serve to clarify their perception and attitudes, identify the relationship of family attitude with the treatment of the child, determine expectation and aspiration related to the disabled child and evaluate the nature of the family problems associated with the disabled child.

The investigation of perception of disability by parents and siblings will reveal how they see ^{the} child's disability, to what extent they are aware of the cause, what do they feel about the child's special ^{needs,} and the possibility of arranging special education for the child. Similarly, an exploration into the nature of aspiration will identify the hopes families attach for the disabled child in spite of his deficiencies regarding education, occupation, marriage and life settlement.

Exploration of expectations of parents and siblings for the disabled child will reveal what they expect the child to do in future, ^{and} how realistically ~~it~~ they have related the expectations with the child's limitations. Do they expect too much of him or do they underestimate the child?

The problems identified by parents and siblings related to the disabled child will assist people working in the field of special education to design better strategies to be adopted while working with the families of disabled children. It will enlighten the areas where more effort is required by service providers when involving parents in educating disabled children.

Since special education is a ~~relatively~~ new field of study in Pakistan, the investigation will provide much needed information, ^{and} ^{encourage} ~~hopefully~~ future research. The favourable parental attitude, as brought to light by this investigation will encourage a new and effective approach of parental involvement in the teaching of handicapped children.

This study will reflect not only the educational aspect but will also provide an insight into the trends of social behaviour and social interactions in our

community. Based on the findings of the study, the investigator will make suggestions and recommendations for parents as well as teachers which will support growth of the disabled child.

Definition of important concepts:

Generally the terms used in the study pertain to their popular connotations but there are a few terms which need clarification. They are defined in the context of their use in the study;

Disabled:

The term disabled may be taken as "a person with functional limitations to carry out the normal activities of daily living caused by either a permanent physical or mental impairment or a chronic clinical condition such as epilepsy, bronchitis or schizophrenia". (Williams 1981)

Mental retardation:

Mental retardation refers to significantly sub-average general intellectual functioning existing concurrently with

deficits in adaptive behaviour manifested during the development period i.e., 0-18 years. (Drew 1981)

Perception:

Perception refers both to the experience of gaining sensory information about the world of people, things, and events and to the psychological processes by which this is accomplished. The present investigation however, takes the term as 'the awareness of truth related to the child's disability'. (Corsini 1987)

Attitude:

An attitude is an idea charged with emotion which predisposes a class of actions to a particular class of social situations. (Horne 1985)

Aspiration:

Aspiration is the desire, hope or aim towards which one strives. The term is taken to explore the hopes parents and siblings have for the child and it is interpreted by the future aims they have for the child. (Harriman 1977)

Expectation:

Expectations refers to. 'the anticipated outcome of a probabilistic situation, an emotional state of anticipation'. Expectations in this study reveals the hopes parents and siblings attach with the child about his future achievements. (Kuper 1985).

Sibling:

The term refers to sister or brother, a child of the same family. (Kuper 1985).

Limitations of the study:

Keeping in view the shortage of time, energy and resources the study has the following limitations.

- ✓ The study is confined to Kuvendi City only, its findings are therefore, generalisable only to a similar location.
- ★ The target population in the study was mentally retarded children. Children with other disabilities were not included.
- * The units of the study are father, mother and one elder sibling of the disabled child.
- * The study is of exploratory nature and therefore, no

claim is made about its comprehensiveness or representativeness.

Objectives of the study:

The study focussed on following :

1. To study perception of disability by the parents and siblings.
2. To analyse the prevalent attitudes of parents towards disabled children.
3. To identify different types of parental attitudes.
4. To investigate relationship between family attitude and care provided to the disabled child.
5. To explore the aspirations of parents and siblings for the disabled child.
6. To find out the expectations parents and siblings have from the disabled child.
7. To enquire into the problems faced by parents ^{and} siblings of disabled children regarding education and care.
8. To explore the differences in perception, aspiration, expectations and problems faced by parents and siblings of disabled children.

Research hypotheses:

1. Parental attitude is associated with identification of the mental retardation in a child.
 - * Those with a favourable attitude identify the disability early.
 - * Those with a negative attitude identify the disability later.
2. Parental attitude^{is} related to the provision of education to disabled children.
 - * Parents with a favourable attitude provide formal education to their disabled children.
 - * Parents with^{an} unfavourable attitude do not care much about the provision^{of} formal education of the child.
3. Parental attitude is related to the treatment meted out to the children at home.
4. Parents education is related with the identification of child's disability.
 - * Those with higher education identify the disability earlier.
 - * Those with lower education are less concerned with the disability of the child.
5. Higher the occupational status of the father, the greater the concern for the future of the child.

6. A joint family system is related to identification, treatment and education of the disabled child.

- * ~ Joint family adversely affects the identification of the disabled child.
- * ~ Joint family negatively affects the availability of medical support for the child.
- * ~ Joint family negatively affects the handling and training of the child.