

CHAPTER — III

DESIGN OF THE STUDY

Selection of the subject:

The sample for the study was derived from the sampling frame of a previous study conducted at Jinnah Post Graduate Medical Centre in the Department of Neuropsychiatry between the 1986 and 1988, aimed at identifying disabilities in children (Mehtar, 1991). Since one of the aims of the study was to estimate the prevalence of childhood disability in Karachi city, an existing sampling frame, utilizing a cluster sampling strategy devised by the Applied Economic Research (AERC) Centre of Karachi University was employed.

The AERC aggregated the 241 master plan development zones of Karachi Development Authority into 59 larger zones, termed as 'Analysis Zones' which included 43 primarily Urban zones and 16 primarily rural zones. Finally, to draw a sample of several thousand children, 9 of the 43 Urban zones and 3 of the 16 rural zones were selected for the survey. Besides, within each of the 12 zones, a randomly selected block of continuous households were selected, making a total

of 2807 household to get a representative sample of Karachi city (Meher, 1991). The survey of the selected households screened 6365 children: out of which 937 (14.7 percent) were identified as disabled having physical handicap, mental handicap, hearing impairment and visual handicap.

The method of identifying categories of disability involved complete assessment of the child by a doctor as well as a psychologist. The doctor carried out medical check up while the psychologist administered ^{the} Binet-Simon Intelligence Scale (R-1983) and ^{the} Adaptive Behaviour Scale (Modified) to detect ^{the} child's problems. On the basis of the test results, a joint decision was given regarding the child's disability. From this sampling frame, 44 households categorised to have mentally retarded children were selected for the present study.

As ^{the} size of the sample is small, it was supplemented by the cases drawn from special schools for mentally retarded children in Karachi. Only the children identified as mentally retarded on the basis of medical and psychological assessment were considered for the study. This provided a sample of fifty six making a total of hundred cases for the study. The two samples were treated together as

it provided a representation of upper middle class, middle class, lower middle class and lower class of the population.

The sample selected was from the areas of Clifton, Defence Housing Authority, Gulshan-e-Iqbal, North Nazimabad, Federal "B" Area, Shah Faisal Colony, North Karachi, and Saddar. The age of the sample in the study ranged from 1 to 24 years. One adult from each household primarily concerned with the care of the disabled child or available at the time was interviewed. The interviews were conducted during home visit by the investigator.

Later on the other parent was interviewed to find concordance in perceptions, their expectation for the child in ^{the} future and their desire of accomplishment and family problems related to the child's disability. Considering the possibility of the perceptions, expectations, aspirations and problems of the siblings at variance with parents, it was deemed appropriate to interview a sibling of the child. As such, one elder sibling was interviewed from each household.

Utilizing ^{the} direct interview method, the investigator

visited each household to interview the respondent. In this connection, great problems were faced as some of the respondents could not spare time for the interviewer because of their own commitment *such as* responsibility of household affairs, job, care of children etc. The investigator had to visit again and again and request for cooperation. Despite all efforts, in some cases ^{the} visits proved to be a failure.

It was with regard to this difficulty that the sample was restricted to hundred cases. In the cases, where the other parents were to be interviewed, specially the father, the interviewer had to visit at different time schedules as per their availability. In some cases the other parent did not exist, was living out of the city or could not be available despite repeated efforts. Because ^{of} all these reasons, the number of parents interviewed later could not match to the original number i.e., hundred parents. The total ^{number of} parents interviewed later was 71. The number of the siblings also could not match the number of parents because of the conditionality of *siblings' age and parity order*. Only 27 siblings could be interviewed for the study.

The educational status of the respondents (parents) was matriculation or bachelor's degree in majority ^{of the} cases followed

by intermediate, primary level or no formal education. The number of highly qualified respondents was least represented in the sample. The age range was between twenty to sixty nine while the major occupation was clerical jobs, typing, office work or technical responsibilities. Only a smaller group was found involved in business, teaching and other semi skilled or skilled labour.

The educational status of the respondents (siblings) however differed from that of the parents as most of them were between the ages ten and fourteen years. Most of the siblings of the disabled child were students and ^{only a few} were found engaged in any type of jobs. Majority of the group had a primary or secondary education while least number had higher secondary, bachelor's degree or masters degree. ^A small group had no formal education.

Description of the instruments:

The study was carried out to obtain information from one parent/guardian, other information on selected items from the other parent and certain information from the siblings. Therefore, three questionnaires were developed, the first containing 55 items, the second 36 and the third for siblings

33 items. The instruments of the study were structured schedules to be used while interviewing the respondents. All the questions were framed to reflect the research problem and its hypotheses.

There were three major sections in the first questionnaire. The first section was designed to determine the characteristics of a disabled child. Section two contained general information about the parents of the disabled child and section three comprised specific questions on parental attitudes and its stated influences on the disabled child. The questionnaire used both precoded items as well as some open ended items framed for indepth information.

The second questionnaire obtained information about some of the items from the initial questionnaire and some additional details. This questionnaire included 5 sections. First part obtained the general information about the case, second, parental perceptions of disability, the third aspirations, fourth expectations and the last, problems associated with the child's disability.

The questionnaire for siblings included questions about their age, sex, educational status, occupation as well

as their perceptions, future aspirations, expectations and problems created due to the existence of the disabled child. The areas explored included the nature of child's disability, behavioural manifestations, causes^{of disability}, perception and behaviour of others towards the child, educational provision for the child, future planning as well as the problem associated with the child's disability, like emotional pressures, stigmatization, socialization, etc.

The drafts of the questionnaire were pre-tested before it was finally developed. The main objective of pretesting was to examine the suitability and effectiveness of questions in eliciting adequate responses and to find out if there were any language problems faced by the respondents. It also helped to determine the approximate time required to complete a questionnaire. After making minor revisions in the questionnaires, they were prepared for the study. The questionnaire was developed both in English and Urdu languages and used keeping in view the ease of the respondents.

The three questionnaires are given in appendix C.

Data collection:

The process of data collection started from North Karachi, proceeding towards Federal B. Area, Defence Housing Authority and other areas of Karachi. The researcher approached the respondents, visited the houses of the disabled children and gathered data through direct interviews. The responses were recorded in the questionnaire on the spot. The process of data collection took a period of one year.

The second phase of study included interview *with* the other parent and the elder sibling. For this purpose, the investigator after a lapse of a few months again went in the community, contacted parents and siblings and collected data through interview/on the questionnaires prepared for them.

The data were coded on the coding scheme developed for open ended questions used. The data thus coded were transferred on the summary sheet for manual processing. Since the investigator *did* not have an access to a computer and the help of a computer expert and considering the small *sample* of the study, the analysis was done manually by the investigator. There was no problem in the tabulation of data

for the precoded items but where free responses were made. the data had to be coded. For this purpose, the investigator read all the responses herself before developing the codes for these items. Personal involvement in the coding and analysis helped in avoiding ambiguities and errors.

Statistical analysis:

General tables were prepared, and the frequencies and percentages were analyzed. This was confined to calculating frequency and percentage. For some items cross tabulation were conducted. For items which were included for testing hypotheses, contingency tables were designed. Chi-square was calculated through these tables to find out significant differences between groups on specified variable. Where conditionalities of X^2 test were not rich, test of difference between two proportions were used.