CHAPTER - 3

RESEARCH METHODOLOGY

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3.1 INTRODUCTION

The family is characterized as a diverse and evolving social system. Regardless of the structure of the unit, the family is centered on an emotional bond between parents and children. The family provides a socially acceptable vehicle for bringing children into the world. As seen in the previous chapter the presence of a Mentally Retarded child does cause additional burden and disturbance in a family.

3.2 RESEARCH DESIGN

This study initially intends to understand the socio-demographic background of families with Mentally Retarded children. Later focuses on the social problems faced by parents of Mentally Retarded children.

The study intends to find out the effects of age of the child, Gender and level of retardation of the child while analyzing the social problems faced by the parents of Mentally Retarded children.

Descriptive study focus on the portrayal of the characteristics of a group and it is related largely to the present, and abstracting generalizations by the cross sectional study of the current situation and also analyses the views of the target population. Hence this study will be based on the descriptive design.

3.3 OBJECTIVES OF THE STUDY

The general aim of this study is to understand the social problems of parents of Mentally Retarded Children.

1. To study the socio-demographic background of parents having Mentally Retarded children.

2. To assess the burden on daily routine of parents of Mentally Retarded Children.
3. To study the problems faced by the parents of Mentally Retarded children within their family.

4. To study the problems faced by the parents of Mentally Retarded Children in the society.

5. To study the problems experienced by the parents of Mentally Retarded children in various areas like finance, occupation and health.

6. To study the problems experienced by the parents in educating their Mentally Retarded children.

7. To study the association between socio-demographic variables and the major subject dimensions studied.

8. To study the social support systems available in the society for the parents having Mentally Retarded children.

9. To assess the social support system as perceived by the parents of Mentally Retarded children.

10. To identify suitable measures for parents to cope with Mentally Retarded Children.

3.4 HYPOTHESES

Based on the above objectives, the following research hypotheses were framed to have a detailed understanding of the study.

1. There is a significant difference between the gender of the child and social problems of parents.
2. There is a significant difference between the social problems faced by the fathers and mothers.

3. There is a significant difference between the social problems of parents and their area of living.

4. There is a significant difference between the type of family and social problems of parents.

5. The nature of occupation has an impact on social problems of the parents.

6. There is a significant association between the religion of parents and level of social problems.

7. There is a significant relationship between the age group of Children and level of social problems of parents.

8. Higher the level of retardation of the child, Higher the level of social problems for parents.

9. Age of Parents have significant association with level of social problems.

10. Educated parents have high level of social problems.

11. There is a significant association with the family income and financial problems of parents.

12. Level of retardation of male children has significant association with level of social problems of parents.

13. Level of retardation of female children has significant association with level of social problems of parents.

14. Age of male children have significant association with level of social problems of parents.
15. Age of female children have significant association with level of social problems of parents.

16. The area of living has association with the awareness level of parents about the Governmental and Non-Governmental help.

17. The Nature of Occupation has association with the awareness level of parents about the Governmental and Non-Governmental help.

18. Age of the children has an impact on the awareness level of parents about the Governmental and Non-Governmental help.

19. Level of Education of parents has association with the awareness level of parents about the Governmental and Non-Governmental help.

20. Level of Awareness about social support systems depends on the level of income of parents.

3.5 CONCEPTUAL FRAME WORK

Raising a child who is Mentally Retarded requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children, and parents can find themselves overwhelmed by various medical, care giving, financial and educational responsibilities. Whether the special needs of the child are minimal or complex, the parents are inevitably affected. Support from family, friends, the community or paid caregivers is critical in maintaining the balance in the home.

Emotional Issues

Parents of Mentally Retarded children commonly experience a gamut of emotions over the years. They often struggle with guilt. One or both parents may feel as though they somehow caused the child to be disabled, whether from genetics,
alcohol use, stress, or other logical or illogical reasons. This guilt can harm the parent’s emotional health if it is not dealt with. Some parents struggle with “why” and experience a spiritual crisis or blame the other parent. Most parents have aspirations for their child from the time of her birth and can experience severe disappointment that she will not be president, a physician, an actor or whatever they had in mind. Occasionally, parent feels embarrassed or ashamed that their child is Mentally Retarded.

There are a few studies in India that have demonstrated that the presence of a child with Mental Retardation can cause emotional reactions like stock-guilt etc (Seshadri, et al., 1983; Narayan 1979) increase in interpersonal conflicts among family members (Jain & Sathyavathi, 1969), social isolation (Narayan, 1979) and added responsibilities (Jain & Sathyavathi 1969). However there is a paucity of systematic research related to the understanding of the social problems of parents with Mentally Retarded Children. The present research is an attempt to study the perceived social problems of parents having children with Mental Retardation.

**Physical Exhaustion and Stress**

Physical exhaustion can take a toll on the parents of a Mentally Retarded child. The degree of this is usually related to the amount of care needed. The Mentally Retarded child may have more physician and other health-care appointments than a typical child and may need close medical monitoring. The child may also need to be watched to avoid inadvertent self-harm such as falling down stairs or walking into the street. These additional responsibilities can take a physical toll on a parent, leading to exhaustion.

Stress experienced by families of children with Mentally Retarded does create burden to the family in many areas and disrupts family functioning as well. It is logical to think that if stress is associated with parenting a disabled child, the marital
relationship and family functioning will be vulnerable to the effects of that increased stress as well.

**School-Related Issues**

The parent of a child with Mentally Retarded may have to deal with complex issues related to education. Either a private education must be sought, or an adequate public education must be available. Parents often have to advocate for their child to receive a quality educational experience that will enrich her/him. This often requires close parental contact with the school system. The parent must monitor the child’s interactions with others to ensure that she/he is not being bullied. Transportation to and from school may require a specialized bus or van, and children with severe disabilities may need to be schooled at home.

**Job related concerns**

Parents with Mentally Retarded children have to depend on others to look after their child, when they go to their work place. The parents also believe that their work performance level gets affected and they lack concentration in their job or business. They are reluctant to accept any transfers or change of job because of the responsibilities associated with the care of Mentally Retarded child. They may have to sacrifice their job to take care of the child or they have to move to an area where rehabilitation servicers available for their retarded child.

**Financial concerns**

Raising a child with a Mental Retardation may be more expensive than raising a typical child. These expenses can arise from medical equipment and supplies, medical care, care giving expenses, private education, tutoring, adaptive learning equipment or specialized transportation. The care of the child may last a lifetime
instead of 18 years. Parents may have to set aside money in a trust fund for the child’s care when they pass away.

**Social concerns**

Research has documented that the child with mentally Retarded may also influence functions related to meeting basic family needs, self-identify needs, economic needs, daily care needs, recreation needs, socialization etc. The responsibilities associated with the care of children with Mental Retardation may have an impact on the parent’s psychological, physical, financial and social well being over time (Seligman & Myerson, 1982 venture & Boxx, 1983. Gallagher et al., 1983; quine & Paul 1985)

The presence of a child with Mental Retardation may also curtail the recreation needs and often imposes social restrains on the family (MC Andrew, 1976, ROOS 1977, Wickler, 1981, Strain, 1982, Skrtic et al 1984, Vadaszy et al 1984; Brotherson, 1985; Gold farb et al 1986). Parents may also develop low self esteem which in turn affects social integration and social participation of the family members.

Taking all these factors into considerations the intention of this research is to understand the social problems of parents having Mentally Retarded children and to suggest the available social support systems which maximize their social integration. The grandparents and siblings have not been considered as part of this study.

This study focuses mainly on social problems of parents of Mentally Retarded children under seven major dimensions. Namely;

**Burden on daily routine**

Parents of Mentally Retarded children have to give complete assistance to their child through out the day, which results in total up set of the routine work at home, office, etc.
Problems faced within the family

Other members of family are reluctant to attend the Mentally Retarded child’s needs and they even tease the parents. Friends and relatives avoid visiting the house. Even the marital life is in question between the parents of Mentally Retarded child.

Health problems

Almost all parents of Mentally Retarded children are worsely affected both physically and mentally. They become depressed and ailments such as high blood pressure, sleeplessness, heart burn, diabetics are commonly found among the parents. There are many parents with intension to commit suicide.

Education of the child

Availability of special schools is limited and very difficult to get admission in special school which is suitable for the child’s needs. The fees are in higher side and proximity to the special schools is also in question.

Financial problems

Parent’s financial position gets worsened due to the expenses towards educational fees, therapy charges, medical expenses and care taking of Mentally Retarded child. The parents have to limit the expenses for self and for other children in the family.

Problems faced in the job

Parents of Mentally Retarded children have to depend on others to look after their child when they have to go to work place. They are not able to expose their job skills and they cannot accept any promotions and change in work place due to the non – availability of rehabilitation centers and special schools for their child.
Problems faced in the society

The Mentally Retarded child becomes mockery to other children and people do not accept the presence Mentally Retarded child in functions and in areas of recreation, which causes mental stress to the parents and they have to live a secluded life.

3.6 DEFINITIONS OF TERMS

Problem

A problem is an obstacle which makes it difficult to achieve a desired goals objective or purpose. It refers to a situation, condition, or issue that is yet unresolved. In a board sense, a problem exists when an individual becomes aware of a significant difference between what actually is and what is desired. Every problem asks for an answer or solution.

In society, a problem can refer to particular, social issues, which if solved would yield social benefits, such as increased harmony or productivity and conversely culminated hostility and disruption.

Social Problems

Situations affecting a significant number of people that are believed to be sources of difficulty or threaten the stability of the community, and that require programs of amelioration.

Society

A long-standing group of people sharing cultural aspects such as language, dress, norms of behavior and artistic forms.
**Parent**

A parent is a father or mother, one who gives birth to and/or nurtures and raises an offspring. The different role of parents varies throughout the tree of life, and is especially complex in human culture.

**Mother**

A mother is the biological or social female parent of a child or offspring. The maternal bond describes the feelings the mother has for her (or another’s) child. In the case of a mammal such as a human, the mother gestates her child (called first an embryo, then a fetus) in the uterus from conception until the fetus is sufficiently well-developed to be born. The mother then goes into labour and gives birth. Once the child is born, the mother produces milk to feed the child.

**Father**

A father is traditionally the male parent. Like mothers, fathers may be categorized according to their biological, social or legal relationship with the child. Historically, the biological relationship paternity has been determinative of fatherhood. However, proof of paternity has been intrinsically problematic and so social rules often determined who would be regarded as a father e.g. the husband of the mother.

**Children**

Authors of English Dictionaries (Brown, 1993; Simpson & Weiner, 1989; Hughes, Michell & Ramson, 1992) provide various definitions also for a child (plural, children):

- A young human being below the age of puberty
- An unborn or new born human being
- One’s son or daughter at any age
Mental Retardation

Mental Retardation is a term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with mental retardation may take longer to learn to speak, walk and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be some things they cannot learn.

IDEA’s – Definition

Our Nation’s Special Education Law, the IDEA (Individual with Disabilities Education ACT) defines mental retardation as. “Significantly sub average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child’s educational performance”.

1995 – PD Act – Definition

“According to the person with disability (Equal opportunities, protection of Rights and full participation) Act 1995” Mental Retardation means a condition of arrested or in complete development of mind of a person which is specially characterized by sub normality of intelligence.

DSM IV - Definition

According to DSM IV Mental Retardation is defined as significantly sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas. Communications, self care, home - living, interpersonal skill, use of community resources, self-
direction, functional academic skills, work, leisure, health and safety with an onset before age of 18 years.

**AAIDD - Definition**

According to American Association on Intellectual and Developmental Disabilities Mental Retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

**Social Integration**

Social Integration can be seen as a dynamic and principled process where all members participate in dialogue to achieve and maintain peaceful social relations. Social integration does not mean coerced assimilation or forced integration.

**Social Support**

Social Support means the resources that are provided by other persons (Cohen & Syme, 1985). It is a multi-dimensional construct that includes physical and instrumental assistance, attitude transmission, resources and information sharing and emotional and psychological support (Dunst and Trivette, 1986).

Social support is understood as “whatever it takes” to increase the family’s ability to care for their child, improve the quality of the family’s life and prevents the child with a disability from having to live outside his/her natural home. The intervening effect of mediators like social support will enable parents to cope up better with the situation thus minimizing the effect of problems they face in the family and in society.
3.7 TOOLS FOR DATA COLLECTION

For the purpose of collecting information for the study, a Questionnaire in TAMIL language which consists of 170 questions, under 2 major sections was used. A brief description of the tools is presented here. Additional information of the tools is appended.

The Initial data collection was done with a self prepared socio-demographic schedule. The schedule elicited information of the respondents on age, sex, relationship to the child, area of residence, family type, occupation, income and religion. It also consisted of items pertaining to the Mentally Retarded children in the family. Information was obtained regarding the age, sex, and level of retardation of the child.

3.8 VARIABLES

Independent variables related to child

- Age
- Sex
- Level of retardation

Independent variables related to parents

- Age
- Sex
- Education level
- Family income
- Nature of family
- Area of residence
- Religion
- Occupation


3.9 UNIVERSE AND SAMPLING

Parents with Mentally Retarded Children were chosen as the universe for this study. This study was conducted at 8 special schools for Mentally Retarded Children in Greater Chennai.

Namely:

1) Sathyalok School for the Special Children
2) Don Guanella Society for the Rehabilitation of the Disabled
3) Carmel Centre for Mentally Retarded
4) Balavikas Special School for the Mentally Retarded
5) Therisa Rehabilitation Centre for the Disabled
6) Maithree’s School for the Special Children
7) Puthuir School for the Special Children
8) Balavihar School for the Special Children

Details of the universe are given below:

The sample includes parents of children with Mental Retardation. The sample consists of either mothers or fathers based on the mutually defined inclusion criteria.

The census method was adopted and all the parents of Mentally Retarded children within the age group of 4-18 years from the above mentioned special schools are included to study the social problems of parents of Mentally Retarded children. A census is a count of all the elements in a population.
3.9. A. NUMBER OF CHILDREN WITH MENTAL RETARDATION ACCORDING TO THE AGE IN 8 SPECIAL SCHOOLS

<table>
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<tr>
<th>S. No.</th>
<th>NAME OF THE SCHOOL</th>
<th>NUMBER OF CHILDREN</th>
<th></th>
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<td></td>
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<td>BOYS</td>
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<td>GIRLS</td>
<td>BOYS</td>
<td>GIRLS</td>
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<td></td>
<td></td>
<td>AGE</td>
<td>4-8</td>
<td>9-13</td>
<td>14-18</td>
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<td>1.</td>
<td>Sathyalok School for the Special Children</td>
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<td>23</td>
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<td>12</td>
</tr>
<tr>
<td>2.</td>
<td>Don Guanella Rehabilitation Centre</td>
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<td>17</td>
<td>18</td>
<td>45</td>
<td>6</td>
</tr>
<tr>
<td>3.</td>
<td>Carmel Centre for Mentally Retarded</td>
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<td>9</td>
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<td>4.</td>
<td>Balavikas Special School</td>
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<td>8</td>
<td>40</td>
<td>9</td>
</tr>
<tr>
<td>5.</td>
<td>Therisa Rehabilitation Centre</td>
<td>9</td>
<td>14</td>
<td>12</td>
<td>35</td>
<td>4</td>
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<tr>
<td>6.</td>
<td>Maithree’s School for the Special Children</td>
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<td>7.</td>
<td>Puthuir School of the Special Children</td>
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<td>8.</td>
<td>Balavihar School for the Special Children</td>
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<td>97</td>
<td>151</td>
<td>110</td>
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</table>

BOYS  = 358  
GIRLS  = 192  
TOTAL = 550
3.10. PILOT STUDY

The researcher undertook the pilot study to ascertain the feasibility of conducting the research. Visits were made to the respective special schools in Greater Chennai to obtain permission from the school authorities to conduct the study with the parents who have children with Mental Retardation in their school. The purpose and need of the study was explained to the school authorities and the parents. Suggestions and opinions were obtained from the parents and these were incorporated in the study. The total number of children in each school was ascertained and their level of retardation, and chronological age was also noted. Based on this information the tools were finalized and dates were decided for data collection.

3.11. PRE-TEST

The questionnaires were tried on a small sample of 10 respondents during the pre-test. The parents were called for a meeting in the school and were explained the process of data collection. A few questions were included in the schedule. The total time to ascertain the responses from these respondents was found to be one hour. The final form of the questionnaire was thus determined.

3.12. DATA COLLECTION

The scales were administered to the sample of 550 respondents. The respondents from each special school were called for a parents meeting by the schools. These respondents were briefed about the aim of the study and the answering mode. They were then administered with the questionnaires. Item wise explanation was given in the vernacular. The responses to the scales were scored with the help of the scoring key to obtain an overall index for all the scales. Data collection was carried out from June 2009 to February 2010.
3.13. PROBLEMS ENCOUNTERED BY THE RESEARCHER:

- The parents had to be assembled in the special schools at a particular day and time to collect the details. But not all parents had come as specified. The researcher then made home visits to collect the information.

3.14. LIMITATIONS OF THE STUDY:

- The present study has been done only with parents of school going children with mental retardation. Many children, who are in home based care, have not been included in the purview of the research.