CHAPTER III

Methodology

3.1. Statement of the problem

The study titled “Impact of Community Based Rehabilitation Programme on Children with Mental Retardation and their Caregivers in the Rural Areas of Ramanathapuram District, Tamil Nadu, India” is an attempt to understand the implementation aspects of the Community Based Rehabilitation (CBR) Programme and its impact on the child beneficiaries with mental retardation and their caregivers in the rural settlements. This was studied through quantifying the functional improvement in the children and changes in the perceived problems of their caregivers, using appropriate measuring tools.

Community Based Rehabilitation is a process conceived in 1970’s to empower the Persons With Disabilities and their families to take care of their needs in every sphere of their lives (WHO, 1989). In India, the CBR programme was initiated in the 1980’s. The approach implies that the families of children with disabilities play a vital role in making CBR programme effective. It utilizes the existing and local resources in the rural community and thus leads to restoration of the Persons With Disabilities to function at their optimum level. It also tries to integrate a network of services available for the disabled through the welfare programme, family members and other support groups.

According to National Institute for the Mentally Handicapped (2001) the persons with mental retardation in India constitute 2 to 3 percent of the total
population i.e., around 20 million persons. Around 80 percent of the persons with mental retardation live in the villages or in urban slums, where rehabilitation services are limited and sparse. The possibilities are less to get all of them included in welfare schemes and programmes provided both by the government and nongovernmental agencies. At the same time it is not just a challenge to reach out these people but a conscientious human obligation (Jeyachandran, 2001). Is Community Based Rehabilitation programme an attempt aimed at fulfilling this obligation? This study is an attempt to understand and assess the achievement of the programme in this line.

3.2. Conceptual framework

Community Based Rehabilitation has been conceived as a strategy to serve the needs of Persons With Disabilities. The conceptual framework is given in the figure 3.01. The programme is delivered to the beneficiaries and other target groups by the collective task force including government officials, specialists and field workers, NGOs and local volunteer groups at village, block and district levels. The specialists on the task force are Physiotherapists, Audiologist, Speech Therapist, Ortho technician and Training Coordinator. They work at district level under the District Disability Rehabilitation Officer (DDRO) and District Medical Officer (DMO). A Multipurpose Rehabilitation Worker (MRW) and two Special Educators (Early Intervention) work at block level. Two Community Based Rehabilitation Workers (CBRWs) serve on the team at Panchayat level.
The NGOs who are accountable for the successful implementation of the programme in Ramanathapuram district are Vijay Human Services, Chennai and World Vision India, Muthukulathur. For the successful implementation of the programme voluntary groups and local volunteers have been identified and integrated on the team for service delivery.

The beneficiaries of the programme are the Persons With Disabilities in the district jurisdiction and their primary caregivers and family members. The intervention components provided to the Persons With Disabilities include restorative interventions, provision of special as well as inclusive education, imparting vocational training and welfare measures. At the family and community level, the Community Based Rehabilitation strategies attempt to change their Knowledge, Attitude and Practice (KAP) levels on disability, its prevention and management and strengthening support services at various levels.

The impact of the programme is periodically assessed using both quantitative and qualitative techniques. The changes in the adaptive behaviour of the Persons With Disabilities, the perceived problems of the caregivers and their KAP levels on disability prevention and management are quantifiable. Interview, observation and participatory techniques are the qualitative devices used in the evaluation process. The focused and systematic pre and post assessment of the changes in the adaptive behaviour of the Persons With Disabilities and the perceived problems of the caregivers would reveal the success of the intervention provided.
Figure 3.01
Conceptual Framework of CBR Programme

**GOs**
- District Level
  - DDRO-1
  - DMO-1
- Block Level
  - MRWs-1
  - SE-2
- Village Level
  - CBRWs-2

**NGOs**
- Vijay Human Services
- World Vision India

**Voluntary Groups**
- SHGs
- Local Volunteers

**Persons With Disabilities**
- Disability Intervention
- Vocational Training
- Improving access to services

**Family & Community**
- Awareness Generation
- Training in Disability Prevention & Management
- Advocacy

**Persons With Disabilities**
- Adaptive Behavioural Changes

**Caregivers**
- Perceived Problems
- KAP levels on Disability Management and Prevention

**Experiences (+ve/-ve)**
- Challenges
- Problems
The feedback of the positive and negative experiences encourages refinement in the intervention procedure and will pave the way for making effective improvements in the intervention process. This in turn will lead to perfection of the services at all levels including governmental, nongovernmental and voluntary groups to modify the Community Based Rehabilitation strategy.

3.3. Hypotheses

• There would be a significant improvement in the adaptive behaviour of children with mental retardation on intervention under the CBR programme

• The age, gender and levels of retardation of the children with mental retardation would significantly influence the improvement in their adaptive behaviour after the CBR intervention.

• There would be significant changes in the perceived problems of the caregivers of the children with mental retardation on intervention under CBR programme

• The age, gender and the level of retardation of the children would significantly influence the changes in perceived problems of the caregivers.

3.4. Design of the Study

A survey design was followed for this study, which is evaluative in nature. The study aims at describing the improvements in the adaptive behaviour of children and changes in the perceived problems of their caregivers.
on subjecting them to the interventions under CBR programme. Both qualitative and quantitative assessments were made. The former was done for understanding the background of the Persons With Disabilities and their caregivers, the problems faced by the CBR personnel and to gather their suggestions for overcoming the problems. The quantitative assessment was carried out to measure the changes in the adaptive behaviour of children with mental retardation and the perceived problems of the caregivers.

3.5. Area of the study

Ramanathapuram district was chosen as the study site. It is one of the most backward districts in Tamil Nadu state. This district has been ranked second in rural poverty and sixth in Tamil Nadu in overall poverty (Human Development Index, 2000). Ramanathapuram is located in the southeastern coastal area of Tamil Nadu and is surrounded by Sivagangai, Pudukottai, Virudhunagar and Thoothukudi districts, Palk Strait and Gulf of Mannar. Ramanathapuram district has an area of 4123km$^2$ and has a population of 1,183,321 as per 2001 census. The density of the population is 297 per sq km (VHS, 2003). It is located on the latitude N9°05' to 9°06' and longitude of E 78°01' to 79°02'. Average rainfall of this district is 949mm. Ramanathapuram district is a major tourist centre and is one of the main pilgrim centers in India. Rameswaram Temple and Erwadi Darha (Mosque) are the main pilgrim centers.

In 1910, Ramanathapuram was formed by clubbing portions from Madurai and Tirunelveli district. During the British period this district was
called “Ramnad”. The name continued after independence. Later the district was renamed as Ramanathapuram to be in conformity with the Tamil name for this region. This district has a plain terrain with sedimentary rocks. Vaigai, Gundar, Kottakarai and Virusuli are the main rivers of this district. Agriculture is the main source of income of the families. It depends on rainfall, which is very fickle in this area. The other main income sources of the families in this district are fisheries, salt pan, conventional pyrolysis, small scale palm sugar industries, basket weaving etc.

The district is backward in terms of economic productivity and it has poor access to resources, educational institutions, employment opportunities, and transport facilities, sanitation etc., (VHS, 2003). Nutritional deficiency is common among rural population and consanguineous marriage is a general practice among all communities. Community ‘We’ feeling and own ness is very high in this district.

The' block wise distribution of children with mental retardation in Ramanathapuram district is shown in Table.3.0l. A total of 741 children were seen distributed in the eleven blocks and their distribution ranged from 47-86 per block with a mean of 67.3 persons. Further, the children with mental retardation under the age group of 3-15 years constituted 6.9 per cent of the total population of Persons With Disabilities (PWDs) and 37.4 percent of the Persons with Mental Retardation (PMR) in Ramanathapuram district.
Table 3.01

Block wise Distribution of Children with Mental Retardation in the Age Group of 3-15 years in Ramanathapuram District

<table>
<thead>
<tr>
<th>Name of the Block</th>
<th>Number</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandapam</td>
<td>77</td>
<td>10.40</td>
</tr>
<tr>
<td>Thirupullani</td>
<td>79</td>
<td>10.70</td>
</tr>
<tr>
<td>R.S.Mangalam</td>
<td>82</td>
<td>11.10</td>
</tr>
<tr>
<td>Thiruvadanai</td>
<td>68</td>
<td>9.20</td>
</tr>
<tr>
<td>Muthukulathur</td>
<td>86</td>
<td>11.60</td>
</tr>
<tr>
<td>Kadaladi</td>
<td>69</td>
<td>9.30</td>
</tr>
<tr>
<td>Ramanathapuram</td>
<td>60</td>
<td>8.10</td>
</tr>
<tr>
<td>Kamuthi</td>
<td>61</td>
<td>8.20</td>
</tr>
<tr>
<td>Bogalur</td>
<td>47</td>
<td>6.30</td>
</tr>
<tr>
<td>Paramakudi</td>
<td>59</td>
<td>8.00</td>
</tr>
<tr>
<td>Nainarkovil</td>
<td>53</td>
<td>7.10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>741</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Source: District Rehabilitation Centre, Ramanathapuram (2003).

The main reasons for selecting Ramanathapuram district for the present study was it is one among the three districts in Tamil Nadu where Government of India initiated National Programme for Rehabilitation of Persons with Disabilities (NPRPD) programme.

3.6. Study Sample

Six blocks of Ramanathapuram district were randomly chosen as the study area by odd numbering. They were, Mandapam, R.S. Mangalam, Thirupullani, Ramanathapuram, Bogalur and Nainarkovil.
Plate-3.01
Data Collection

Creating Rapport With
The Caregivers Through
DRC

Interviewing The
Caregiver

Adaptive Behaviour Assessment Kit
(ABAK)

Assessment Of Adaptive
Behaviour
Table 3.02

Children with Mental Retardation in the Study Area

<table>
<thead>
<tr>
<th>Name of the block</th>
<th>Actual population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Mandapam</td>
<td>57</td>
</tr>
<tr>
<td>R.S. Mangalam</td>
<td>60</td>
</tr>
<tr>
<td>Muthukulathur</td>
<td>59</td>
</tr>
<tr>
<td>Ramanathapuram</td>
<td>40</td>
</tr>
<tr>
<td>Bogalur</td>
<td>27</td>
</tr>
<tr>
<td>Nainarkovil</td>
<td>33</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>276</strong></td>
</tr>
</tbody>
</table>

Source: District Rehabilitation Centre, Ramanathapuram, 2003.

As shown in table 3.02, totally 276 children with mental retardation in the age group of 3-15 years were enumerated from the records maintained in the District Rehabilitation Centre of Ramanathapuram. Of the 276 study subjects, the families of two children could not be located and for seven children the families were not supportive during the course of the study. The remaining 267 children and their caregivers constituted the study population.

3.7. Data collection Procedure

The data collection was planned in four phases. In the first phase the details of the CBR programme and its implementation aspects were gathered. During the second phase the background details including personal background of the children, their familial and socio economic status, problems associated with retardation, health complaints and reported etiological factors were studied through a detailed survey at household level. The assessment of the
adaptive behaviour of the children with mental retardation and the perceived problems of the caregivers was done as part of the household survey using appropriate scales. The third phase of the data collection included the post intervention assessment of the adaptive behaviour of the children subjected to the intervention and the perceived problems of their caregivers. The last phase of the study was an attempt to identify and shortlist the problems experienced by the staff working at grass root level under the CBR programme and further to elicit their suggestions for overcoming their problems at work site.

Tools and Techniques

Interview Schedule: A schedule was framed for conducting the household survey and interview was the method chosen for data collection in the field. The schedule had questions relating to children’s personal details, family background, socio-economic status, factors associated with retardation and reported etiological factors all in a sequence. The schedule was validated by getting it judged by experts in the field and necessary modifications were made based on their suggestions. (Appendix-1).

MBPS scale: To assess the adaptive behaviour of children under the study the Madras Developmental Programming System (MDPS) scale developed by Jeyachandran and Vimala (2000) was chosen. The reasons for choosing the scale were (a) This scale is widely being used all over India to assess the adaptive behaviour of the children with mental retardation (b) it has more regional reliability and (c) this scale was already being used by the SSA-IED in Ramanathapuram district. This scale had 360 items grouped into 18 functional
domains of 20 items each. They are Gross motor activities, Fine motor activities, Meal time activities, Dressing skills, Grooming skills, Toilet skills, Receptive language, Expressive language, Social interaction, Reading skills, Writing skills, Number skills, Time skills, Money skills, Domestic activities, Community orientation, Recreation and Leisure time activities and Vocational activities. The MDPS scale chosen for the study contains components like the behavioural scale, the behavioural profile, the Adaptive Behaviour Assessment Kit (ABAK), which contains assessment tools. The Individualized Programme Plan (IEP) of the MDPS Scale alone was not included in this study, as this study has not included IEP component.

The Inter-rater agreement coefficient of the scale was 0.86. Its test - retest reliability coefficient was 0.94. The Cronbach’s Alpha of internal consistency of the scale was 0.94 (Jeyachandran and Vimala, 2004). The reliability of the scale was thus very high face validity of MDPS scale has also been reported high. Since those tests had been done in Tamil Nadu, no regional variations were expected. Hence the scale was accepted as such for measuring the functional capability of the children. The MDPS scale is presented in Appendix-II.

**Scale for assessing the perceived problems of the caregivers:** The final part of the data collection tool was a scale to measure the perceived problems of the caregivers due to child’s retardation. The investigator prepared a list of statements, based on the literature on problems of the caregivers. The list of statements was given to a panel of twelve experts in the field of Clinical
Psychology, Social Work and Home Science to establish face validity. The panel evaluated the scale and agreed that the list of statements were sufficient for the assessment of perceived problems of the caregivers. They were requested to rate each of the statements on a three-point scale. Based on the jury ratings, some statements were deleted and some were reworded or regrouped under fourteen heads such as, Physical burden, Health problems, Financial constraints, Employment level, Perception of restricted feeling, Feeling of ridicule and embarrassment, Perception of insecure feeling, Perception of distorted thought, Perception of family support, Perception of community support, Perception of family harmony, Perception of sibling reaction, Perception of positive attitude and Perception of recreation and leisure time activities. Ninety percent of the jury opinion was favourable to the test. This scale is presented in Appendix-III.

The schedule with the scale developed by the investigator for assessing the perceived problems of the caregivers was pre-tested with 20 families having children with mental retardation. This facilitated the investigator to improve the reliability of the responses by improving the internal consistency and clarity of the questions.

Collection of Data

Phase 1: **Perusal of records and reports:** During the first phase the investigator visited the District Rehabilitation Centre and the center of the CBR programme in Ramanathapuram district to gather details of the children with mental retardation in the study area and the CBR programme and its
implementation strategies. The visit enabled the investigator to establish rapport with the field staff of CBR programme.

Phase 2: **Household survey:** Interview was chosen as the method for household survey primarily because the procedure facilitates ample interaction with the respondents to elicit the required information. Moreover, it provides opportunities to indepth observation and is an ideal method to deal with illiterate and semiliterate respondents. The caregivers of the children were the primary respondents of the study. The household survey was done from December, 2003-June 2004 and this almost coincided with the initiation of the CBR programme that commenced in Ramanathapuram district in September 2003.

Prior to data collection, the investigator met the field staff of CBR programme and the Special Educators of SSA-IED (Sarva Shiksha Abhiyan-Integrated Education for the Disabled) of the respective blocks and explained the purpose of the study. They in turn helped the investigator to locate the respondents and build rapport with them and further to minimize the social distance from the family members of the children with mental retardation.

Baseline survey was conducted for all the 267 respondents. Friendly and informal conversations with the caregivers on their problems related to childcare activities had strengthened the relationship between the investigator and the respondents.

Out of the 267 children selected for the study, 11 children with profound retardation were excluded from the assessment of adaptive behaviour by MDPS
scale considering their inability to respond to the intervention. All the remaining 256 children were selected for the assessment of adaptive behaviour. The domains of MDPS scale were assorted according to the frame of mind and ability of the children with mental retardation during the administration of the instrument.

The perceived problems of the 267 caregivers were also assessed by using the modified scale developed by the investigator. The caregivers were interviewed face to face and the children were assessed at their residence in one to two sittings. One full interview and assessment process took normally 50 to 60 minutes. Cross checking was made then and there with the help of the Community Based Rehabilitation Workers (CBRW), Multipurpose Rehabilitation Workers (MRWs) and the Special Educators of SSA-IED. This enabled the investigator to ensure the reliability of the responses.

**Phase 3: Post intervention Assessment:** The post intervention of the programme was done in June-November, 2005, that is after one year of the initiation of N'PRPD programme. Since the CBR intervention was planned and executed in four quarters, each extending for a period of three months, the impact analysis of the programme was done after the minimum period of one year. It was ensured from the records and the respondents that they had a minimum contact period of one year with the CBR personnel prior to administering the tests. The scales used initially for assessing the adaptive behaviour of the children and the perceived problems of the caregivers were
readministered and the differences in the pre and post intervention scores were compared to make a judgement on the intervention.

**Phase 4: Participatory Rural Appraisal (PRA) method.** A modified technique of PRA called **Visualizing and Participatory Planning** was used to elicit information on the problems they have encountered and their suggestions to minimize the predicaments and to maximize the available resources for the successful implementation of CBR programme. A team of 32 members working with the children and their families participated in the PRA. They included 16 Community Based Rehabilitation Workers (CBRW), six Multipurpose Rehabilitation Workers (MRW), eight Special Educators of SSA-IED and two Physiotherapists.

The group was divided into two by odd numbering to have an optimum size of 16 each to conduct the PRA. Parallel sessions were held for each team after general instructions on the procedural modalities and rules of PRA. The procedure followed for conducting the **Visualizing and Participatory Planning** technique was:

- Selected a Visualizer and a Facilitator within the team members for smooth conduct of the PRA.
- The investigator explained the steps to the Visualizer and to the Facilitator to conduct the PRA.
- Each member of the team was given three cards to enter his or her problems.
- On each card, the team members were asked to write only one problem.
• Visualizer collected the filled in cards and read out to the group the responses one by one and fixed them on the board.

» Similar ideas were fixed on the board in clusters.
• The cards according to the responses were sorted, grouped and regrouped.
• Missed responses were discussed and added by consensus.
• The problems were labeled under ten heads and
• The problems were prioritised according to the frequency of repetition.

The groups were combined for a panel discussion and the responses from both the groups were displayed and discussed. Again the missed responses were discussed and added by consensus. The responses were finally prioritized. The whole process took approximately six hours.

**Scheme of Analysis**

The data were edited, coded, tabulated and analyzed by using SPSS. One-way and two-way tables were used for tabulation. Percentages and statistical measures such as Mean, Standard Deviation were calculated to present the characteristics of the study sample. Chi Square test for ascertaining the association between dependant and independent variables, t’ test and ANOVA were used to understand the difference in the variables before and after intervention.

### 3.9. Delimitations

1. The study focused only on the problems of adaptive behaviour. The attributes regarding problem behaviour could not be studied as resistance were noticed from some of the family members.
2. The problems of fathers, siblings and grand parents were not studied in detail, as it required ample time stretch.

3.10. Limitations of the study

1. Since the interview process required repeated visits in many cases the pace of data collection was very slow.

2. All the children with mental retardation in the study area could not be reached easily due to poor transportation facility.

3. The study was synchronized with the field work timings of Special Educators and CBRWS. So the study could not be completed within the prefixed timeframe.

4. The limitations of the survey technique will be reflected in the study findings though sincere efforts were made by the investigator to improve the reliability of the responses.