

SUMMARY AND CONCLUSION

CHAPTER VI

SUMMARY AND CONCLUSION

6.0 INTRODUCTION

The Government of India had set up a Kothari Commission (1964-66) and it is for the first time. The Commission has thought over the equalization of educational opportunities without any consideration of race, caste and community. Two historic legislations enacted in the nineties have provided education of children with special needs in India a sound direction and solid footing. One is "Rehabilitation Council Of India Act (1992)" and another is, "the Persons with Disabilities (Equal opportunities, Protection of Rights and Full participation) Act (1995)". Every human being has equal rights and requires all types of facilities not only for his maintenance and physical up keep but also for his proper education or training. Special education for children with mental retardation has grown rapidly in the last two decades. Special education is instruction designed for students with disabilities or talents who also have special learning needs. Some of the students have difficulty learning in regular classrooms, they need special education to function in school. To fulfill these special needs, special curriculum has to be dealt with the special methods of teaching and training.

A child who is below average in intelligence is labeled by different terms. These include terms like: mental defectives, mentally subnormal, mentally retarded, mentally challenged, intellectually defective, intellectually subnormal, intellectually retarded, oligophrenic, feeble minded, amental, exceptional and slow learning.

The most commonly and recently accepted definition was developed by the American Association on Mental Retardation (AAMR). It is a professional organization that specializes in problem of people with mental retardation and developmental disabilities. According to AAMR definition, mental retardation is: "Significantly sub average general intellectual functioning resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period" (Grossman, 1983).

AAMR definition describes four levels of mental retardation: Mild, Moderate, Severe and Profound

Individuals with low intelligence have been classified in following ways

Psychological		Educational	
Level	I.Q.	Level	I.Q.
Mild	55 – 70 approx	Educable Mentally Retarded	50-75
Moderate	35 – 55	Trainable Mentally Retarded	25 – 30 to 50
Severe	20 – 34	Custodial Mentally Retarded	below 25
Profound	Below 20 or 25		

Diagnostic and Statistical Manual of Mental Disorder, American Psychiatric Association ,1994.

AAMR(1994) new definition of mental retardation no longer labels individuals according to the categories of mild, moderate, severe and profound mental retardation based on IQ level. It now looks by at the intensity and pattern of changing supports needed by an individual over a lifetime The four level of supports are:

- ❖ Intermittent support-support on an “as needed basis.” Support that is not needed on a continuous daily basis.
- ❖ Limited support- support over a limited time span, such transition from school to work or to job training
- ❖ Extensive support – support needed on a daily basis, but not necessary in all life areas.
- ❖ Pervasive support- constant support that may include life-sustaining measure. Daily support across all life areas.

There were many misconceptions held both by the general public and by professional worker during 18th century. Some of these were that mental deficiency is a disease, that delinquent and criminal behaviours are a direct consequence of mental deficiency, that education is of no value in the treatment of mental deficiency, and certain others. There are still some misconceptions prevalling in the society

There was very little provision made for either their special education or training

In the early part of the 20th century, some attempts at differentiation in the segregation and treatment of the individuals with mental retardation began to appear. Institutions and special schools were established for their care and training. During the 1950s and 1960s, a growing concern for the children with mental retardation developed and parents of the retarded started to organize.

Normalization, mainstreaming, and integration as innovative practices have glittered the corridors of special education in recent years.

There are many factors that cause mental retardation. Some factors are known and some are still unknown. The conditions that occur before the birth of a baby i.e. when the child is in the mother's womb, during delivery and after the birth of a baby may lead on to mental retardation (between conceptions to 18 years of age).

Trends in the field of mental retardation are changing rapidly. More attention being given to it and more parents wanting their children to be given equal opportunities in the community and in the schools.

6.1 PARENTAL INVOLVEMENT IN TRAINING THEIR CHILDREN WITH MENTAL RETARDATION

The institution of family is considered essential for the existence of society. Parenting is a complex, dynamic process that affects both parent and child. The parents learn the art of parenting as they bring up their children.

If parents are adequately and properly informed at the right time about parenting the child with disability, that is early in the life of the child, a great amount of strain and stress on the part of the parents can be reduced. Usually parents become aware of the child's problem in preschool years or after he enters the school if the nature of the disabling condition is mild.

The stress is being placed more in trying to identify, classify, and properly place the child with mental retardation in a programme where he is capable of succeeding and working according to his own capabilities. Parenting is a complex, dynamic process that affects both parents and child. A parent develops and uses the knowledge and skills required to plan for their children, give birth to them, and / or rear and care for them (Morrison, 1978) Before a child can be expected to make adequate school and community adjustments,

he must have learned to make reasonable home adjustments. The home, or some proper substitute situation provided through the home, has the responsibility for the physical care and health maintenance of the child with mental retardation. As far as he is able to do so, the child should be taught to care for his own physical and health needs. It is in the home that the child must learn to walk and talk. The home has the responsibility for the child's all important early language learning. It is the responsibility of the parents to provide the experiences to the child that acquaint him with his environment. Another important responsibility of parents at home is to inculcate in child with mental retardation a socially acceptable habits and attitudes.

6.2 FAMILY INTERVENTION PROCESS

Family intervention is a method by which a professional tries to enable the family to solve problems or help to develop skill to face problem situation with stability. Family Intervention process can be described through three major stages:

- ❖ Beginning Stage
- ❖ Diagnostic Stage
- ❖ Winding up Stage

If there is no intervention, the family continues to have stress, which leads to severe pathology in the family functioning due to the ignorance and apathy in the family. Timely help and intervention enhances family's strength to cope up with the crisis situation. Parents are the child's first and most influential teachers.

The underlying concept of family-centered intervention is that children's functioning can be maximized by providing services that are designed to enhance the effectiveness of their families. Families are interactive, interdependent systems with individual members reciprocally affecting each other

To enhance the effectiveness of the family it is important to identify the needs of individual family members, locate resources for meeting those needs and help to guide family members in utilizing these identified sources

Parent intervention programme has a positive effect on children's academic achievement increasing the chances of success in life. Parental involvement in training early the growing period of life of the child enables development of positive attitude in the parents towards the child, acquisition of knowledge and skills in training the child and development of confidence in them in handling their child on their own.

Parent education increases the parents' competence, as they are the child's primary teachers in the home. Parents learn effective instructional and behaviour management techniques and positive communication skills.

6.3 PARENTAL NEED

In addition to common parent concerns about their children's social development, physical health, educational and vocational preparation and capacity for independent functioning in the community, parents of children with mental retardation have several additional concerns like child's self acceptance and acceptance by others, the availability of specialized education and training programmes. The greatest single need of parents of children with mental retardation is constructive professional counseling at various stages in the child's life which will enable the parents to find the answers to their own individual problems to a reasonably satisfactory degree. The concerns vary in intensity from family to family and within a particular family over time.

Generally the common felt needs of the parents of the children with mental retardation are:

6.3.1 Handling Behaviour Problem of the Children with Mental Retardation

Problem behaviours could be due to a number of reasons. From a behavioural point of view, it may be due to lack of communication skills, cognitive skills or problem solving skills. Due to the presence of behavioural problems, children with mental retardation may find difficult to get admission in schools, cause embarrassment to the parents and family members due to the presence of socially unacceptable behaviours. It is important for the service providers to know what the various behaviour problems are posed by persons with mental retardation to their parents for which they seek professional help.

Parents have been found to benefit a lot from training programmes that help them to become better behaviour modifiers of their own children.

6.3.2 Emotional Needs of Parents

The birth of a child with mental retardation is a traumatic experience for every parent. There are number of questions that immediately arise in the minds of the parents. There are certain expressive aspects of parenting an exceptional child:

- (i) Initial – crisis reaction
- (ii) Mourning and sorrow
- (iii) Denial
- (iv) Avoidance and rejection
- (v) Guilt
- (vi) Anger and hostility
- (vii) Self-doubt
- (viii) Withdrawal and depression
- (ix) Embarrassment and social isolation

Coping behaviours include acceptance and love and hope. After a period of coming to terms with the feelings about parenting an exceptional child, parents being to 'think and behave constructively thereby facilitating development of the child's human potential.

As their crisis reactions lessen and parents become more accepting, they see more reasons to feel good about themselves and their special child. Parents develop faith that they, with others, can and will help their special child reach his or her fullest potential.

Parents are empathetic. They not only know the facts of exceptionality but they also know how it feels.

To cope with these emotional traumas yoga gives strength to face it. Yoga *Sadhana* is important for freeing the mind of various psychogenic diseases. Children with mental retardation can be treated up to a great extent with the help of yogic techniques. This may also become very useful for stress and anxiety disorder that the parents usually face. However, parental training is very necessary

6.3.3 Role of Parents in the Activities of Daily Living Skill Training to the Children

With appropriate interventions, most individuals with mental retardation can learn at least some basic self-care skills like toileting, bathing, dressing etc. The extent to which individuals with mental retardation can be trained to look after their basic needs depends on the severity of their handicap, it is still important to look for ways in which they can be encouraged to become increasingly independent, it is possible that with proper training, opportunities and experiences an individual with mild and moderate mental retardation with no significantly associated conditions can achieve mastery of self care skills.

With appropriate training, opportunities and experiences given to the child with mental retardation at home, the child will learn and perform at his best.

There are certain other skills, which are essential for vocation for individuals with mental retardation i.e. cognitive skills, personal skills, social skills, safety skills and work related skills. The single most factors in vocational rehabilitation are the support and attitude of the family which can be a major source of accurate information about the person's interests and capabilities.

6.3.4 Awareness about Government Benefits and Concession

Persons with mental retardation have got the right to avail services and facilities, which are available specifically for their functional and social integration.

During the past two decades, several schemes have been launched by the Ministry of Welfare and Social Justice, Government of India to support rehabilitation services viz. VRC - Vocational Rehabilitation Centres, medical fitness, educational, vocational and employment, facilities for training and research in all areas of disability by establishing National Institutes or introducing these programmes in existing National Institutes

Thus it is essential to cater to the parents' needs first and accordingly plan an intervention programme.

RESEARCH QUESTIONS:

While researching into the subject of the study, some vital questions that emerge are as follows:

- Q.1. What are needs of the parents having children with mental retardation in rearing the them?
- Q.2. Will intervention programme help the parents to fulfill their perceived needs regarding the children with mental retardation?
- Q.3. How far is it feasible to develop an effective intervention Programme which should be adequate to cater to the needs of parents?
- Q.4. Can intervention programme bring any change in the awareness level and the attitude of the parents towards their children with mental retardation in parenting and in helping to resolve some of their problems?
- Q.5. How far can it be effective in alleviating the stress and anxiety due to child with mental retardation?
- Q.6. What will be the effectiveness of such a programme in respect of the long-term gain in the lives of the children with mental retardation?

To address the research questions enumerated above, the present study is undertaken.

6.4 RATIONALE OF THE STUDY

No work with the people having mental retardation could succeed, if their parents are not involved. Firstly it is important to understand them and their emotional difficulties. They should be helped to overcome or at least minimize their difficulties. Secondly, they should be guided in ways of helping to overcome specific problems of their child. The children with mental retardation are special group of children. For their optimum development in all aspects, early interventions are essential. Parents are their first teachers at home

The greater the number of unmet needs, the greater the number of emotional and physical problem reported by parents of children with mental retardation. This includes stress, negative feelings towards the child. The greater the number of needs unrelated to child-level interventions, the greater the probability that the parents indicate that they do not have the time, energy and personal investment to carry out such interventions One of the most

important issues in teaching and training persons with mental retardation is how best one could transfer the skills learnt in one setting by person with mental retardation to natural settings i.e. home. As parents would have direct contact with their children in various settings the problem of transference could be solved to a great extent. Also it is estimated that the effects of training would stay longer when parents are directly involved with their children with mental retardation. Home teaching occurs in the natural environment of the parents and their ward. What needs to be taught at school first and then transferred to home can be directly taught at home. Some skill behaviours such as bathing, toileting, brushing teeth, combing, dressing, occur naturally in the home situation than in artificially created conditions at the day school. These skills can be best taught at home by involving parents in the teaching and training programmes of their children with mental retardation. By educating parents for their basic help in rearing and developing their wards with better scientific understanding and training, the ultimate education reaches to the children with mental retardation for their functional life.

To achieve a wholesome family balance for all members of the family unit is the optimum goal of the intervention programme so that these children may be enabled with true dignity to find a real place as part of a living family group. Effectiveness of a programme depends to a great extent on parents' cooperation and involvement. Unfortunately, though literature is appearing now in India, but it is mostly concerned with the mentally deficient as a whole and not with the problem faced by the families. Review of related literature showed that there are some Indian and International studies carried out to find out the effectiveness of training programme to the parents of children with mental retardation. Evaluation of the programme is done only on the basis of pre and posttest results. Very few follow up studies / home visits were undertaken to get the indepth information. These research lacunae necessitated indepth study followed by concrete action.

The present study tries to assess the needs of the parents of children with mental retardation and an attempt is made to develop the intervention programme and study its effectiveness. The findings of the study may give directions for further research in this area.

6.5 STATEMENT OF THE PROBLEM

"Development and Try-out of an Intervention Programme for Parents of Children with Mental Retardation".

6.6 OBJECTIVES OF THE STUDY

1. To assess the needs of the parents of the children with mental retardation in order to plan an intervention programme.
2. To develop an intervention programme for parents of children with mental retardation.
3. To implement an intervention programme for parents.
4. To study the effectiveness of the intervention programme.

6.7 EXPLANATION OF THE TERMS

Explanations of the important terms used in the study are given below for the sake of clarity.

EFFECTIVENESS

It refers to the amount of learning that is purported to have been produced in the parents by exposing them to a particular programme and the amount of learning they are able to practice with their children. Here effectiveness will be seen by comparing pre-test and post-test scores and also by follow-up techniques (through observations, anecdote, field diaries). Effectiveness in terms of increase in awareness, confidence in facing and solving problems, rational understanding and attitude toward problem of their wards.

INTERVENTION PROGRAMME

An approach designed to change or impact upon a specific task or area of growth of a specific problem or area of deficit for development tasks or skills. It is a need-based programme for parents having children with mental retardation. The intervention programme was designed to develop skills in the parents to overcome or minimize their stress; anxiety related to their child and his/ her upbringing healthy. By making them aware about their concern areas of

knowledge and helping them to solve their problems and even to help themselves.

MENTAL RETARDATION

It refers to substantial limitation in present functioning characterized by significant and sub average intellectual functioning (IQ below 70), existing concurrently with related limitation in two or more of the adaptive skill areas like communication, community use, self care, social skills, self direction, functional academics and work (AAMR, 1983). The recent definition of mental retardation no longer labels individuals according to the categories. It now looks at the intensity and patterns of changing supports needed by an individual over a lifetime. Children with mild and moderate mental retardation who goes to any special or integrated school were considered in the study. Children with mild mental retardation are slower in learning and understanding as compared to normal children. They can look after their own day-to-day needs. Children with the moderate mental retardation can learn to do routine work under supervisions. They can learn to look after themselves if they are properly trained.

6.8 DELIMITATIONS OF THE STUDY

- (i) The study is delimited to the parents having children in the age group of 8 – 15 years mild or moderate mental retardation.
- (ii) Parents of the children, who are going to any special institution / school.

6.9 SAMPLE OF THE STUDY

Multi stage sampling was selected as the sampling techniques. In the first stage of sampling, Baroda city was chosen purposively. A complete list of special schools / integrated schools for children with mental retardation was prepared.

In the second stage of sampling, a sample of three special schools and an integrated school for children with mental retardation was selected randomly from the list of schools. In each of the selected schools, a complete list of children was prepared with the permission of the school authorities

From this complete list, again randomly twenty-five children were selected, who have mild or moderate mental retardation.

Parents of these children were interviewed for need assessment who acted as the respondent for the present study.

Parents' willingness and cooperation throughout the study was ensured and only those parents were included in the sample that had shown these aspects.

6.10 TOOLS AND TECHNIQUES

Following tools were used to collect the necessary quantitative and qualitative data for the study.

- ❖ Identification Data Sheet
- ❖ Observation Schedule
- ❖ Family Needs Assessment Schedule (NIMH – FAMNS)
- ❖ Pretest and Posttest Questionnaire
- ❖ Anecdotal Records
- ❖ Case-Studies
- ❖ Reaction Scale for Feedback of the Intervention Programme

IDENTIFICATION DATA SHEET

Data sheet was prepared by the investigator to collect general information about the child with mental retardation and his or her family. This includes information such as personal characteristics of the participant and child characteristics.

OBSERVATION SCHEDULE FOR PARENTS

Observation before and after the intervention programme were made in the following areas:

- ❖ Attitude of the parents towards their child with mental retardation.
- ❖ Efforts to help and cooperate the child in his daily activities and behavioural aspects.
- ❖ Acceptance of child's disability.
- ❖ Minimize the parents' anxieties / stress through yoga techniques.

FAMILY NEEDS ASSESSMENT SCHEDULE (NIMH – FAMNS)

The needs of the parents were assessed by using standardized tool developed by NIMH (National Institute for Mentally Handicapped). NIMH-FAMNS, a semi structured interview schedule was developed for the following purpose.

- (i) To identify the needs of the families having individual with mental retardation.
- (ii) To prioritize the needs for family intervention.

There are altogether forty-three items in the semi structured interview schedule, which are grouped under fifteen different areas. Area I includes six items on ‘Information – condition’, Area II has eight items on ‘child management’ comprised managing behavioural problems, daily living activities etc. Area III includes ‘facilitating interaction’. Area IV has items related to the ‘Services’ that are available for the child with mental retardation; Area V includes the vocational planning; Area VI includes marriage aspects; Area VII includes information about Hostel facilities; Area VIII comprised personal and emotional information; Area IX has items related to personal-social aspects; Area X includes ‘support – physical’; Area XI includes needs related to financial aspects; Area XII includes needs related to ‘family relationship’; Area XIII is based on ‘future planning’; Area XIV includes ‘Government benefits and legislation’. The test – reliability coefficient for NIMH family Needs Schedule was found to be 0.75. Their validities were established viz., concurrent validity, and content validity and face validity.

PRETEST AND POSTTEST QUESTIONNAIRE

This tool was prepared by the investigator with the help of experts in the field mainly to measure the parents' level of awareness regarding the concept of mental retardation. The tool has four main parts

Sections	Nature of questions	No. of items
I	Awareness level 3 point rating scale	20
II	Multiple choice Questions	10
III	Open ended Questions	21
IV	Stress Anxiety level 3 point rating scale	10

ANECDOTAL RECORDS

A day-to-day observation record of the children during and after the intervention programme was maintained in the diaries by the parents, which was supervised and monitored by the investigator.

CASE STUDY

In order to get indepth information about the families of children with mental retardation, two case studies showed significant gain on some variables. Investigator collected information through different techniques.

REACTION SCALE FOR FEEDBACK OF THE INTERVENTION PROGRAMME

Participants were requested to give their opinions of the intervention programme in the reaction scale developed by the investigator.

The present research investigation was an intervention study. The study aimed at evaluating changes on a sample of subjects as a result of the intervention programme employed. It was an experimental study. The detailed design of the study has been divided into five phases. The procedural details pertaining to each of the objectives are presented phase wise in the following subsections

6.11 PROCEDURE OF DATA COLLECTION

The details of the data collection are presented phase wise in the following sections:

PHASE I: ASSESSMENT OF PARENTS' NEEDS

After establishing rapport with the parents, the investigator provided the general information sheet to the parents and got it filled. Common felt needs of the parents were assessed by the observation schedule and a semi structured interview schedule. Observed behaviour of the parents and their children with mental retardation were recorded in different situations

PHASE II: DEVELOPMENT AND IMPLEMENTATION OF THE INTERVENTION PROGRAMME

The intervention programme was developed taking into account all the needs of parents which were assessed during the initial phase. Intervention programme was spread over six modules.

- 1) Orientation and Concept of Mental Retardation.
- 2) Concept of Inclusion and Integrated School Approach.
- 3) Behaviour Problems and Behaviour modification techniques for children with mental retardation.
- 4) Vocational Rehabilitation and Employment Opportunities and benefits for the children with mental retardation.
- 5) Self help skills Training.
- 6) Yoga therapy and relaxation techniques for the children with mental retardation and their parents.

There were field visits to vocational rehabilitation centres, K.G.P. children's hospital and Karishma School for children with special needs. Pretest questionnaire were distributed to fill under the prescribed instructions in the first day of the programme.

Booklet named, 'Handbook for the Parents of Children with Mental Retardation' in English and Hindi was developed by the investigator. Folder with an attractive calendar was developed by the investigator in Hindi. List of Vocational Rehabilitation Centres in India were also provided to the parents. The intervention programme was conducted in Hindi to facilitate greater understanding.

Various lectures and demonstrations were provided regarding different techniques of handling children. Two video films developed by 'NIMH' in the form of short stories named 'step by step we learn' and 'manzil ki oar' in Hindi was shown to the parents.

Major common felt needs which were included in the intervention programme were

- (i) General information regarding scientific concept and misconception.
- (ii) Handling behaviour problem of children with mental retardation.
- (iii) Developing daily living skills

- (iv) Employment opportunities for children with mental retardation
- (v) Yoga as a therapy for parents as well as for their children with mental retardation.



PHASE III: EFFECTIVENESS OF THE INTERVENTION PROGRAMME

Daily evaluation report was maintained by the investigator of each session, which includes (i) Change in behaviour throughout the session (ii) Participation in the sessions (iii) Attendance of the parents (iv) Reactions of the parents towards the programme in each session.

Effectiveness of the programme was appraised through

- ❖ Pretest and Posttest questionnaire on awareness level of parents
- ❖ Pretest and Posttest semi structured interview schedule on family needs.
- ❖ Attendance of the parents in the programme
- ❖ Reaction scale.
- ❖ Observation during follow ups through home visits which were evaluated in terms of:
 - Change in attitude and perception of parents as a result of their increased insight.
 - Implementing behaviour modification techniques and for strengthening skill development.
 - Parents' diaries about the child's behaviour progress.
 - Anecdotal records.

6.12 ANALYSIS OF THE DATA

Data were analyzed both qualitatively and quantitatively For the realization of the objective I, to assess the needs of parents of the children with mental retardation in order to plan an intervention programme was measured by observations and by using descriptive statistics.

For the realization of objective IV i.e. to study the effectiveness of the intervention programme, qualitative technique, percentage analysis and t-test were used to compare pretest and posttest scores.

6.13 MAJOR FINDINGS AND CONCLUSIONS

The major findings that have emerged from the study are given below objective wise under separate heads.

(i) ASSESSMENT OF THE NEEDS OF PARENTS OF THE CHILDREN WITH MENTAL RETARDATION

Data regarding the needs of the parents of the children with mental retardation are assessed through observation schedule and semi structured interview schedule.

During the observations it was seen that the parents blamed the children for their behaviour. Two forms of behaviour were found in the parents towards their children – indifferent attitude and sympathetic. It was noticed that behavioural problem of the children which could have been avoided at an early age became more rigid due to lack of knowledge of the parents regarding the training of the children. It was further revealed from the findings that parents usually performed some of the daily tasks of combing, clipping of nails, buttoning, tying shoe laces of their children as parents reported that these children take longer time to learn, so the parents performed certain activities on their behalf which their children cannot perform on their own.

With respect to the emotional reactions of the parents, it was noticed that stress, anxiety and worry were commonly found in parents. Parents expressed immense anxiety regarding the development of self-help skills in their children and acceptable desirable behaviour because they couldn't perceive the child as being capable to learn social skills.

Result showed that different stages of emotions perceived by the parents were:

- ❖ Acceptance
- ❖ Anger
- ❖ Shame
- ❖ Blame
- ❖ Denial
- ❖ Shock

A semi structured interview schedule was used to elicit the needs of the parents having children with mental retardation. Perceived needs of the parents were ranked in frequencies and percentages. Parents reported major needs in 'vocational planning' for their children followed by information on 'services' for training the child. In which majority of the parents had 'greater needs' on 'financial planning' and 'Government benefit for persons with mental retardation'. Again related to 'child management' and 'information-condition', large number of parents needed help in managing behaviour problem in their children as well as in getting cooperation in daily activities. Lowest ranked needs were on 'personal – social' and 'sexuality issues'.

The nature of needs expressed by parents analyzed on two variables namely education of the participant and per capita income of the family

With regards to parents' level of education, findings revealed that majority of undergraduate parents had 'greater needs' to know about the child's condition and majority of the graduate parents needed information on the reading materials related to the child's condition.

The needs for the area of 'child management', majority of the parents who were graduate / postgraduate felt maximum need in handling their children and in getting the child to cooperate in his / her daily activities.

Regarding the area 'services' for children with mental retardation majority of the parents at different level of education indicated greater needs.

It has been observed in the area related to 'future planning', 'financial planning', 'vocational aspects', 'marriage' and 'Government benefit', majority of the undergraduate parents were having greater needs. Higher educated parents reported greater needs in the areas of management of children at home and vocational and future aspects.

Statistically when compared, results showed significant association on decision regarding hostel admission, personal emotional and physical support that includes the need of somebody from institute to drop and bring back the child from school with education of the participant

In relation to the per capita income of the family, findings revealed that parents who have per capita income of Rs 500 – 1500 p.m needed information about the child's condition and almost all income categories were having problems in getting the child to cooperate in his / her daily activities.

Majority of the parents from all income categories again showed 'greater needs' on the services that are presently available for the child. The need for information on 'Government benefits' for persons with mental retardation and their families for persons with mental retardation and their families were greater in the parent of lower income group.

Needs regarding the 'personal – emotional' showed statistical significant association at .05 level of significance with the income group of the parents.

(ii) DEVELOPMENT AND IMPLEMENTATION OF INTERVENTION PROGRAMME

An intervention programme was developed by the investigator taking into consideration the common needs that were assessed during the initial phase. Modules were prepared. Prior to the beginning of the next session, a recapitulation of the previous session was conducted. Programme was started with self-introductory round. Parents were supplied with a kit containing booklet and a folder. Importance of the booklet and the folder was demonstrated to the parents. Programme comprised six modules.

MODULE I: ORIENTATION AND CONCEPT OF MENTAL RETARDATION

Each participant was asked to share his or her views regarding the nature and causes of mental retardation and the misconceptions related to the mental retardation prevailing in the society. Investigator informed about the signs and symptoms which can help in early identification of delayed development in a child and the importance of early intervention programme. In the next component, investigator discussed marriage and sexuality aspects of individual with mental retardation, which was followed by the fruitful discussion.

Further the role of parents in the training and rehabilitation of the child with mental retardation was informed to the investigator. Complete list of regd. parental association in India was also provided to the parents during programme. Two video films developed by 'NIMH' on the concept of mental retardation were shown to the parents. There were several misconceptions related to the cause, nature of handicap and management. Investigator emphasized the need for counseling and public awareness to clear

misconceptions and bring attitudinal changes. Queries emerged were then responded by the investigator / expert.

Second day's discussion was based on two modules viz : Module II: Concept of Inclusion and Integration School approach and Module III Behavioural problems and behaviour modification techniques.

MODULE II: CONCEPT OF INCLUSION AND INTEGRATED SCHOOL APPROACH

Expert started with the concept of inclusion, which has been gaining importance. She informed that the children with or without disability learn together and it helps them to improve themselves socially, physically and intellectually. She added that in special schools, grouping is done based upon mental ages, adaptive functioning level and physical age of children. She stressed that positive aspect of inclusion is that children with mental retardation continue to be educated in a class room along side non-disabled peers and is never pulled out from a class by special teaching.

After this brief concept of inclusion, parents got an opportunity to visit the integrated set up

MODULE III: BEHAVIOUR PROBLEMS AND BEHAVIOUR MODIFICATION TECHNIQUES FOR CHILDREN WITH MENTAL RETARDATION

After giving the brief introductory lecture regarding the behaviour problems, parents were made aware of recording the behaviour and the number of times specific problem behaviour occurs in a given child.

They were informed about the duration recording and time sampling recording and were told to practice so that they can do on their own with their children.

After recording method, they were informed regarding the analysis of behaviour by A-B-C model.

A: What happens immediately before the behaviour? Which has provoked to do the behaviour?

B: What happens during the behaviour? How many times does the problem behaviour occur?

C: What happens immediately after the behaviour? How is the child benefiting by indulging in the problem behaviour?

Investigator then added that certain behaviour modification techniques are used to control some undesirable behaviour. Parents were asked to participate in the short plays. Parents participated and showed the specific behavioural problem of their own children.

Techniques demonstrated were:

- ❖ Anger control techniques
- ❖ Attention seeking control techniques
- ❖ Restitution techniques
- ❖ Time out technique
- ❖ Physical restraint technique

Each parent tried to find at least one undesirable behaviour of their child and tried to relate which technique of behaviour modification would help them best for their child.

MODULE IV: VOCATIONAL TRAINING AND EMPLOYMENT OPPORTUNITIES

Information which was collected from National Institute for the Mentally Handicapped by the Investigator was given to the parents she informed about the prevocational training that there are certain skills and behaviours which are essential for any kind of vocation called prevocation training viz., cognitive skill, personal skills, social skills, life survival skill, safety skills and work related skills.

Investigator made aware of the employment of persons with mental retardation, which includes sheltered employment, open employment and self employment. She added by saying that the type of work selected should appropriate to the retardates capacity and family's ability to manage it

Investigator further informed regarding the Government policies and concessions given by the Government

Fruitful discussions were made after the presentations

MODULE V: SELF HELP SKILLS

Parents were made aware that all children with mental retardation learn easily through small steps. One can split a task into several small steps. Parents were given one activity and were asked to split the task as much as they can. Various illustrations and examples were provided to clarify the concept of task analysis.

Parents were given opportunity to link all steps in sequence of:

- ❖ Shaping
- ❖ Prompting
- ❖ Chaining
- ❖ Modelling
- ❖ Fading.

Investigator informed parents that due to their mental handicap, individuals with mental retardation often lack many thinking tools and observations skills that help to learn even some of the daily routine activities. Thus it is important that individuals with mental retardation can be given training in basic self care at the earliest

Common felt needs on activities of daily living skills were as follows:

- ❖ **DRESSING SKILLS:** How to wear T-shirt, buttoning and unbuttoning were included.
- ❖ **SELF-GROOMING SKILLS:** Combing hair, braiding, clipping nails and cleanliness of nose.
- ❖ **BRUSHING SKILLS:** How to brush teeth systematically
- ❖ **WEARING SLIPPER AND SHOE WITH A LACE.**

Through role play and visual clippings, skills were demonstrated to the parents.

Queries emerged from the session was satisfactory responded by the investigator

MODULE VI: YOGA THERAPY AND RELAXATION TECHNIQUE

Investigator involved parents and their children with mental retardation. Concept and importance of 'yoga' was given to the parents Session was

started with the soft music and parents were asked to concentrate on the music and relax the body. '*Om Kria and Ram Kria*' were performed by the expert. *Asanas*, performed in the sessions, were:

- ❖ Pavanmuktasan
- ❖ Viparit karni
- ❖ Dhanurasana
- ❖ Yogamudrasana
- ❖ Halasan
- ❖ Sarvangasan
- ❖ Sirshasana

After the discussion of the session, at the end, participants were given posttest questionnaire.

The concluding session followed by field visits which has given them the opportunity to the parents to visit and see the functioning of Vocational Rehabilitations Centre, K.G.P. children hospital and Karishma – special school. With these visits, implementation of the programme was concluded.

(iii) EFFECTIVENESS OF THE INTERVENTION PROGRAMME

The data have been collected through

❖ Questionnaire on awareness level of the parents

Results presented the pre-intervention and post-intervention awareness level of the parents in terms of frequencies and percentages. Majority of the parents showed a significant change on the responses at post intervention phase.

At pre-intervention stage, majority of the respondents were not aware of the features of the individuals with mental retardation, regarding the marriage of the individuals with mental retardation, misconceptions regarding the prevention of mental retardation, teaching of children with mental retardation, factors responsible for its cause, better learning with normal peers and importance of special school. While significant change was observed in posttest responses when compared with pretest responses.

Effectiveness was again evaluated by comparing with posttest results of open-ended questionnaire on awareness of the parents regarding mental retardation.

Results of pre-intervention phase indicated that majority of the parents stated that they can give support to their children in terms of basic needs.

Regarding the role of grandparents, majority of them expressed that they can provide financial assistance to the family. With regards to role of siblings, parents again responded that too much involvement will give problems to siblings.

Regarding social interaction, parents viewed that children with mental retardation can communicate with anybody if a child is taught the regional and national language other than his own language.

With regard to management of behavioural problems, majority of them felt that behaviour problem in the child is inborn thereby difficult to manage behaviour problems in a child. Further parents stated that though spending most of the time with index child might affect other family members but their priorities are much inclined towards their wards with mental retardation. With regards to training of the basic needs, majority of the parents felt that making them learn is a time consuming task.

Related to time concept, majority indicated that child needs to have knowledge regarding addition or subtraction then only he could relate the time.

Results further revealed that if the children with mental retardation interact with non-disabled, they will have the inferiority complex.

In relation to the marriage and sexuality aspects, majority reported that if informed properly, then they can look after the family responsibilities to some extent

With regard to the attitude of community towards children with mental retardation, majority of the parents reported that some people are very rigid, so it's difficult to change the attitude of community.

Regarding the hostel admission, parents reported that learning can increase by placing the child in the hostel and child will get exposure.

In relation to the concessions and benefits provided by the Government, few parents were aware regarding the travel concession, where as, with regard

to awareness of parents' associations, majority were unaware of any association.

As far as their work is related, majority of the parents did not have knowledge regarding the employment of these individuals.

Posttest results revealed that parents felt the valuable contribution of grand parents and siblings and themselves in educating the children with mental retardation.

With regard to training in behaviour modification and basic needs, parents opined that these children can be trained in learning the concept of time if he / she knows simple addition and subtraction.

Further they reported that parents should encourage individuals with mental retardation to make friends with non-disabled persons, this will facilitate the acceptance in the community.

With regard to sexual and marriage aspects, majority of the parents showed a change in their responses when compared with the pretest responses. As majority of the parents felt that it depends on the individual, how much severity he/she has; whether he/ she can take the responsibility of marriage. In relation to the scholarship, benefits provided by the Government, majority were aware of travel concession, income tax, family pension etc.

With regard to awareness in 'parents association', and 'employment of individuals with mental retardation, posttest results showed improvement in parental responses. Parents got awareness about certain parents' association in India and were conscience of Vocational Centres and workstations where they can seek help for their children's employment

Effectiveness was again measured in terms of awareness level of parents through statistical technique on pretest and posttest scores. Findings revealed that regarding the cause of the mental retardation, the obtained value of 't' is significant at 0.05 level of significance. With regard to the concept of mental retardation, the mean gain in posttest scores are higher with significant t value except in the statement 'one should not think that person with mental retardation has a small brain whereas a normal person has a broad brain.

Further, in case of child management, 'intensity of behaviour in comparison to intellectually normal person and development of essential skills

into children', it was found that the mean gain was higher but t-test was not found to be significant.

Further effectiveness was measured in terms of parental needs satisfied after the implementation of the programme. It is revealed from the findings, with regard to the 'information-condition', hostel, 'marriage', and 'sexuality', 'child management', 'personal social, facilitating interaction', 'services', 'vocational planning', 'financial', 'future planning' and 'Government benefits', t-value is highly significant at 0.01 level of significance. No significant difference was found in support – physical area.

❖ **Follow ups during home visits**

Follow ups were categorized into three phases

PHASE I (Initial Two Months)

No. of visits: 1st month -once in a week

2nd month- once in fortnight

Parents' attitude toward the child indicated lack of understanding. Few parents were seen forming the groups. A few parents started keeping the records in the diaries. Systematic record of the child's progress was not kept by the parents because they were facing difficulty in maintaining records at each activity with date.

For dressing, grooming, brushing, wearing shoes, majority of the children needed physical assistance. With regard to behaviour modification skills, almost all parents found it somewhat difficult to cope with the management problem of the child. Parents were seen trying techniques like anger control technique and self-management technique to control anger and manage their child's problems. For yoga and relaxation technique, few parents were seen practicing the yoga. Parents found gain in their children when 'Om Kria' was practiced with them.

PHASE II (3 to 5 months)

No. of visits- At the end of each month

Findings of the study indicated that parents indicated an understanding regarding the limitations of such children. They showed the confidence to deal with the children. They seemed enthusiastic about trying out and giving training of the activities to their children. Parents were seen catering the information regarding the Government benefits and concessions.

Parents opined that by training the child in the self-care areas, parents can be relieved from the burden of constantly looking after them. It was observed that parents were modifying the design of dress i.e. large buttons, velcro fasteners and elastic bands. Parents realized the importance of step-by-step training. Significant gain was noticed in dressing skills, brushing skills, wearing shoes with lace, and grooming skills. Verbal and gestural prompting was seen in almost all the skills areas. But in case of skills related to clipping of nails and making plaits of long hair, majority of children still needed physical prompting. Children were enjoying their learning of days and weeks from the calendar.

Almost all parents were seen recording the problem behaviour of the children. Ignoring technique, time out techniques were used by the parents. Some found it effective but still few believed that there is an increase in problem behaviour. Self-management techniques were also used by some parents.

Yogic and relaxation technique were used by the parents during the second phase. Regularity was not seen while performing the asanas in case of some parents.

PHASE III (6-8 months)

No. of visits- once in a month

Parents developed sensitivity in terms of trying to see a problem situation from the child's point of view and understanding his difficulty. Parents were observed to feel less conscious about the child's retardation and exposed him more frequently in the community. They were seen giving a thought to the trusts, which help in financial planning for their children and seen taking the benefits of concessions given by the Government.

They developed insight as to how to make things simple and interesting according to child's ability as they were learnt from the sessions of intervention programme, how to initiate the activity in a step-by-step manner. Gain in activities was observed in dressing skills, brushing skills, wearing shoe with lace (physical prompting is needed in tying the knot and make a bow) grooming skills (where physical prompt is needed in plaiting the hair and clipping the nails of right hand) and time concept. Children became independent in performing activities viz., brushing of teeth, buttoning and unbuttoning of dress and wearing t-shirts. They were performing all the mentioned activities in the systematic manner. During follow-ups, investigator strengthen their learning by providing proper guidelines to parents, helped them to solve the problems by giving better solutions and to recall the things they learnt from the intervention programme.

Now, parents were able to know the cause of the behaviour problem. They realized that they could train their children to make them realize about how they behaved in a specific situation. Self-management techniques, timeout, ignoring techniques, physical restraint were used and proved to be beneficial. Parents opined that with the child's cooperation, they could able to manage the anger.

Tremendous change was found in the children practicing '*Om Kria*' and '*Ram Kria*' regularly. Asanas frequently performed and practiced by the parents were found to be effective.

Change in the physical aspects as perceived by the parents were

- ❖ Mind alert
- ❖ Tongue coordination in the child

Change in the psychological aspects as perceived by the parents were

- ❖ Reduce the feeling of guilt
- ❖ Self control
- ❖ Spiritual advancement

Noticeable change in the responses of the parents was found when stress and anxiety post test questionnaire was administered during last follow ups.

Reaction Scale for Feedback of the Intervention Programme

Majority of the parents got awareness regarding the concept of mental retardation. Methods of conducting the intervention programme were also found to be satisfactory. With regard to 'management of self help skills' and 'behavioural problems', parents could able to manage to an extent. Video films shown during the programme and booklets and folders were also found to be effective. They further indicated that in future these types of programmes should be conducted

6.14 CONCLUSIONS

The major findings given above illustrate the realization of all the objectives of the study to a great extent. The major conclusions that are arrived at from the present investigation revealed that the intervention programme brought the change in the behaviour as the awareness and the skills included in the programme intended to bring desirable changes. Intervention programme enabled parents in identifying needs of their children in various areas. They were able to know the concept of mental retardation and clarify their misconceptions regarding mental retardation. Parents could be able to understand the common behavioural problems and causes of them. Further, intervention programme enabled the parents in identifying different ways of dealing with the problems and tried out techniques to reduce or to manage the behavioural problems in the child.

During the pre-intervention phase, lack of awareness was found among parents regarding mental retardation, which was identified as the major cause of conflicting situation at home. Parents were able to learn certain relaxation techniques to overcome some of the anxieties and stress they were facing day to day while dealing with their children to a large extent. Intervention programme helped parents to know the way they could help their child in learning self help skills Improvement was seen in all the skill development

areas when compared to the earlier level of functioning of the child. The programme could help in bringing out the sensitivity regarding the social benefits provided by the Government. Parents felt that empathetical attitude, understanding and patience towards their children could lead to significant improvement.

It can be concluded that it would bring more positive changes if the parents continue to do so and create a conducive and pleasant environment for learning.

6.15 RECOMMENDATIONS AND SUGGESTIONS

The following recommendations are based on in-depth study of available literature on the subject

- ❖ Coverage in programmes must be increased in the electronic and print media, which promote positive attitude towards persons with disability.
- ❖ Awareness generating programmes should be promoted to cover issues related to disability, schemes/ provisions for people with disability, educational facilities, employment opportunities, and potentials of people with disability, etc.
- ❖ Parents are equal partners in education as teacher for a child, so each and every parent should be given skill based training.
- ❖ Effectiveness of the functioning of Parents Teacher' Associations and different parent groups in the education and rehabilitation of the retarded child may be examined.
- ❖ Organizations of parents should be formed to fight for the rights of the retarded and their families, and to persuade the government to take action for the implementation of various rehabilitative measures.
- ❖ There should be provision for the visit of the itinerant teachers to the homes of the children with mental retardation and thereby helping parents in the home based teaching. So that parents with more number of children can become more involved in the education of their retarded children
- ❖ Adequate support should be provided to the low socioeconomic status parents to properly educate their retarded children and increase their involvement in the education.

- ❖ Sibling and other family members should be encouraged and equipped to participate in the education process of the retarded children. This will help parents to relax and reduce their anxieties about the future of the children, and will keep the family relations intact.
- ❖ The nature of the parent – teacher partnership in the existing special education system may be investigated.
- ❖ Distorted, negative and inaccurate images of persons with disabilities in film, TV serials, radio and television programmes, books, newspapers should not be portrayed and positive and appropriate image should be portrayed.
- ❖ Persons with disabilities should be appointed to decision- making bodies related to media.
- ❖ Discriminatory attitudes towards educating disabled people, with their roots in traditions and unfounded myths, must be replaced with progressive ideas and practices supported by relevant research findings.
- ❖ For the education of children and adults with disabilities there should be sufficient financial, technical and human resources as well as adequate infrastructure for providing education.
- ❖ All teacher-training courses should have the components of special education and for children with special needs.
- ❖ Financial and other incentives must be provided for teachers to acquire special skills and techniques to manage disabled children with special needs
- ❖ NGOs and other professionals with experience in the field of education of disabled children must be involved in preparing training modules for specific age groups of disabled children in the different areas of disability
- ❖ Integration of children with special needs in general education school should be systematically expected.
- ❖ Employers must be reassured that disabled workers can contribute to their production and output and in order to facilitate job opportunities workplaces can be made accessible at low costs. Furthermore, they must understand that impairment is not the same as ill health and disabled workers are punctual and regular in attendance.

- ❖ Advertisements offering job opportunities must be worded with special care to include disabled candidates.

The above recommendations reflect the extent of support systems that people with disabilities currently require. Although there had been a steady increase in the funding of services for disabled people, the actual financial resources are not quite in accordance with their needs and must be improved to avoid negative consequences on the life of disabled people.

In the light of the findings that have emerged from the present study, the following suggestions are drawn for further research.

- (i) The same study may be conducted with a larger sample so that more generalizable findings could be obtained.
- (ii) Present research was only focused on the parents of the children with mental retardation. Another study could be conducted if other family members i.e. siblings, and grand parents are included in the programme.
- (iii) Present focus was on limited number of variables i.e. per capita income and education of the mother with the needs. Effects of other variables such as siblings' birth order, level of retardation could be studied which would give further direction to intervention.
- (iv) Need based intervention programmes could be conducted more elaborately to facilitate coping up strategies amongst parents of children with mental retardation.
- (v) Present research is delimited to the parents. Research study could be conducted if teachers of the school are also involved in the programme.
- (vi) An attempt may be made to carry and try out the self help skills and behaviour modification skills directly to the beneficiaries i.e. children with mental retardation
- (vii) Similar type of programme developed can be tried out in a school in rural areas.