

INTRODUCTION

CHAPTER - I

INTRODUCTION

1.0 CONCEPTUAL FRAMEWORK

Education imparts knowledge, understanding and skill. It is also supposed to develop in each individual a rational outlook and approach to perceive, analyse and adopt the changes taking place all around. The government of India had set up a Kothari Commission on education 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. The Kothari Commission (1964-66) had recommended the education of disabled children in regular schools. The national policy of education, (NPE) 1986 focuses special attention on the education of disabled children for achieving the goal of education for all.

Two historic legislations enacted in the nineties have proved education of children with special needs in India a sound direction and solid footing.

- ❖ Rehabilitation council of India (RCI) Act 1992 passed in the parliament to regulate the training policies in the field of rehabilitation of people with disabilities.
- ❖ The persons with disabilities (Equal opportunities, protections of Rights and Full participation) Act 1995 provides for preventive as well as promotional aspects of rehabilitation, like education, employment and vocational training, reservation and rehabilitation etc.

"Education is the birthright" and their concept is getting momentum in the modern world, heading for the 21st Century. So every country of the world is making efforts to fulfill this basic human and educational need. Education in any society tends to reflect the political philosophy of that society. Every human being has equal rights and requires all types of facilities not only for his maintenance and physical upkeep but also for his proper education or training (Sharma and Rita, 1999). Education is the process of learning and changing as a result of schooling and other experiences. Special education for children with mental retardation has grown rapidly in the last two decades To fulfill the

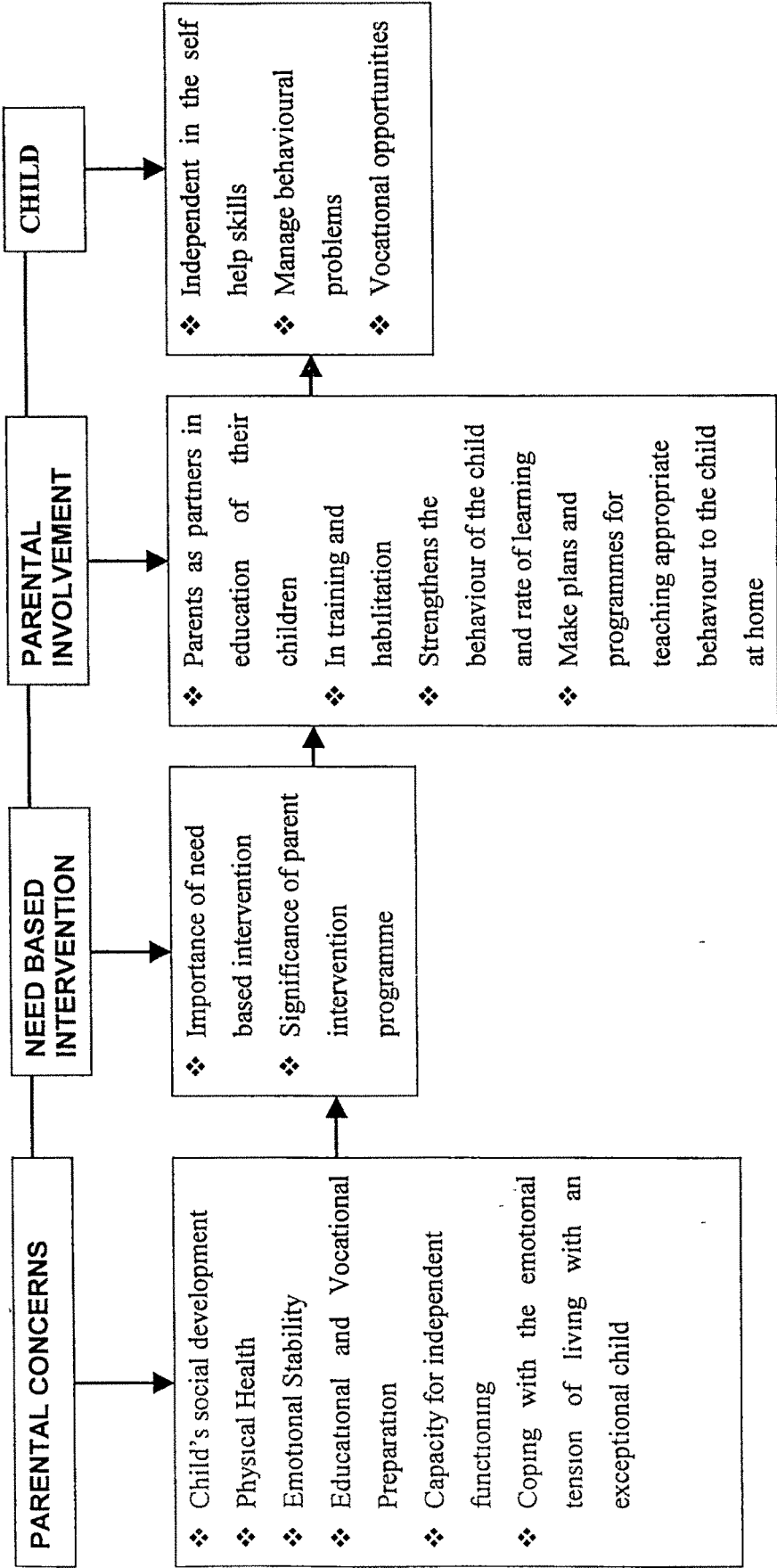


Figure 1.1: SCHEMATIC REPRESENTATION OF THE CONCEPTUAL FRAMEWORK

special needs special curriculum has to be dealt with special methods of teaching. Special education is instruction designed for children with disabilities or talents who also have special learning needs. Some of these children have difficulty learning in regular classrooms, they need special education to function in school. Children are considered exceptional when they

- 1) Meet the criteria for being classified as exceptional
- 2) Require a modification of school practices, or special educational services, to develop to maximum capacity. (Yesseldyke and Algozzine, 1990).

Special classes do not serve as a mere respite for children any more, but individualized educational programmes are tailored for each of the children based on the current level of performance of the child.

Figure: 1 depicts that to aim for conducting need-based intervention programmes, the needs of family would have to be assessed. Based on the goals and assessed needs, focused intervention programmes need to be implemented and evaluated. It also shows that how the parental involvement in the programme is beneficial to the children with mental retardation for their independent functioning and overall growth. Each aspect has been discussed in detail in this chapter.

It has been roughly estimated that 2-3 per cent of most population all over the world are affected by mental retardation. As per the 1991 survey report of National Sample Survey Organisation, India has about nine million children with mental retardation under 14 years of age (RCI, 1996). Nearly 75 percent of the people diagnosed to have mental retardation fall in the category of mild mental retardation, while the remaining 25 percent having IQ 50 or below are classified as moderately, severely or profoundly retarded (NIMH, 1994).

1.1 NATURE AND DEFINITION OF MENTAL RETARDATION

Many "labels" have been applied to the child who is below average in intelligence. These include such terms as: mental defective, mentally subnormal, mentally retarded, mentally challenged, intellectually defective, intellectually subnormal, intellectually retarded, oligophrenic, feeble-minded,

amental, exceptional, and slow learning. In reality there is little difference among them, although some do carry more positively emotional connotations than others. Tredgold, defines mental retardation as a state of incomplete mental development of such a kind and degree that the individual is incapable of himself to the normal environment of his fellows in such a way as to maintain existence independently of supervision control or external support.

Doll's (1941) definition is more explicit than that of Tredgold. He defines feeble-mindedness as mental deficiency is a state of social incompetence obtained at maturity, resulting from developmental arrest of intelligence because of constitutional (hereditary or acquired) origin.

Benoit views mental retardation as a deficit of intellectual function resulting from varied intrapersonal and / or extra personal determinants, but having as a common proximate cause a diminished efficiency of the nervous system thus entailing a lessened general capacity for growth in perceptual and conceptual interpretation and consequently in environmental adjustment (Source: Kirk and Johnson, 1951).

The World Health Organization (WHO) has proposed that those children whose intellectual deficit is sufficiently severe so as to result in academic disability regarded as mentally retarded child

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 problems 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).

"Significantly subaverage general intellectual functioning," means that the individual has an IQ score of less than 68 or 70 on one of the individually administered standard intelligence tests.

"Adaptive behaviour," refers to the skills needed for personal independence and social responsibility such as dressing, toileting, feeding, behaviour control, independence in community and interaction with peers.

"Developmental period" is defined as the time between conception and 18 years of age. An initial diagnosis of mental retardation is commonly to be

made during this period. All three of these conditions must be met to identify an individual as mentally retarded

- 1. An IQ below 70.
- 2. Impairment in adaptive behaviour.
- 3. Occurrence before 18 years.

CLASSIFICATION

Individuals with low intelligence have been classified in various ways. The psychologist classified the individual according to his degree of psychological deficits or indicated by the IQ and other measures. The educator uses the rate of learning or degree of deficit as the basis for organizing an educational programme for the individual. The medical classification is based on the cause The psychological and education classifications are given below in a tabular form.

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,4ed. American Psychiatric Association, 1994).

AAMR definition describes four levels of mental retardation: Mild, Moderate, Severe and Profound. Levels are determined by an individual's IQ on a standardized intelligence test.

AAMR 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 at the intensity and pattern of changing supports needed by an individual over a lifetime. The four levels of support are

- ❖ Intermittent support: Support on " as needed basis." Support that is not needed on a continuous daily basis

- ❖ Limited support: Support over a limited time span, such as transition from school to work or job training.
- ❖ Extensive support: Support needed on a daily basis, but not necessarily in all life areas.
- ❖ Pervasive support: Constant support that may include life sustaining measures, daily support across all life areas.

1.2 HISTORICAL BACKGROUND

Prior to the 20th Century, interest in children with mental retardation had waxed and waned for several hundred years. In the 19th Century, the nature of mental retardation was brought to spectacular public attention by Jean Itard, who undertook the task of educating up to a civilized state" a young boy who had been living in a wild and savage like condition. Itard's training programme is generally considered as the first scientifically documented report of the treatment of a retarded person by means of planned educations. The prevalent theory at that time was that mental defect was amenable to education. It soon became apparent, however, that even though the children placed in special schools did show remarkable growth and progress.

Globally, special education has evolved through four stages. The first stage refers to the stage of neglect and disability was viewed as punishment for past sins and no body wanted to interfere in the justice. This was followed by the stage of pity and compassion, mostly on religious consideration to reduce misery and pain of disabled people. Special school emerged in the third stage. Segregation continued to be the watchword in special education. At the fourth stage, mainstreaming and integration of disabled children in general schools received attention as apart of the normalization movement.

Many misconceptions were held both by the general public and by professional worker during 18th Century. Some of these were that mental deficiency was a disease; that delinquent and criminal behaviours were a direct consequence of mental deficiency; that education was of no value in the treatment of mental deficiency. Thus some attempts at segregation of the mentally retarded individuals was attempted, 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 mentally retarded began to appear. Institutions and special schools were established for their care and training. Probably much desirable attitude was made possible by the development of intelligence tests. In 1904, Alfred Binet and Simon developed the famous Binet-Simon test to identify children with mental retardation. It has been translated and revised for use in many countries throughout the world.

During the 1950s and 1960s a growing concern for the children with mental retardation developed and parents of the retarded started to organize. Currently, the trend in the education of disabled children has taken a turn towards integrated education. This is a positive step towards achieving the goal of normalization. However, this will be successful only when the persons with disability are accepted by the larger community with a positive attitude. Mainstreaming, integration and normalization as innovative practices have glittered the corridors of special education in recent years. The ultimate need for integration of children with special needs into the social fabric of society as functional beings from the Universal Declaration of Human Rights reflected in national aspirations embodied in the constitutional documents in developmental plans. Several countries, both developed and developing have adopted integration as a policy frame for education of children with special need. Most of the developing countries, visualize it as an expedient measure to reinforce efforts to improve access to school as a part of universalisation of basic education. International funding agencies like UNESCO and UNICEF also support it as an alternative to the education of children with special needs in special schools.

1.3 AETIOLOGY OF MENTAL RETARDATION

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 (conception to birth) may lead on to mental retardation.

➤ **Prenatal:**

- ❖ Chromosomal abnormality
- ❖ Genetic disorders
- ❖ Infections in mother
- ❖ Maternal diseases
- ❖ Malnutrition
- ❖ Exposure to X-rays in the early months of pregnancy.
- ❖ Maternal use of alcohol, drugs and smoking etc.

➤ **Neo natal:**

- ❖ Delay in cry due to lack of oxygen
- ❖ Premature birth
- ❖ Low birth weight
- ❖ Trauma to the head of the new born baby
- ❖ Prolonged labour
- ❖ Excessive coiling of the umbilical cord around the neck of the foetus
- ❖ Abnormal position of foetus
- ❖ Severe jaundice in the new born etc

➤ **After the birth of a child:**

- ❖ Severe malnutrition in the child
- ❖ Infection to the child such as meningitis or encephalitis
- ❖ Repeated episodes of epileptic fits
- ❖ Injury to brain from accidents or falls
- ❖ Accidental poisoning etc.

➤ **Other risk Factors**

- ❖ Hereditary factors
- ❖ Child bearing by a woman under 18 years and over 35 years of age.
- ❖ Consanguineous marriage

1.4 POTENTIALS OF INDIVIDUAL WITH MENTAL RETARDATION

Potentials of Persons with Mild Mental Retardation

Mildly Mentally Retarded Individual:

These are also considered as Educable Mentally handicapped. These are those children who, because of retarded intellectual development are incapable of being educated profitably and efficiently through ordinary classroom instruction but may be expected to benefit from special educational facilities designed to make them economically useful and socially adjusted.

Potentials include:

- **Independent functioning:** They can take care of personal grooming, feeding, bathing, and toileting. They may need health and personal care reminders, may need help in selection and purchases of clothing.
- **Physical:** They may be partial mobile and can go to local neighborhood with ease, may use bicycle and other equipment requiring coordination.
- **Communication:** They can communicate complex, verbal concepts and understands them. Carries on everyday conversation, uses telephone and communicate in writing through simple letter writing.
- **Social:** They can interact cooperatively or competitively with others and imitate some group activities primarily for social and recreational purpose, enjoys recreation (dancing, watching T.V.etc.)
- **Economic activity:** One can be sent or can go to shops to make purchases, can make change correctly, may earn living but has difficulty in handling money without guidance.
- **Occupation:** One can cook simple foods, prepare simple meals, and perform everyday household tasks (cleaning and dusting). Adults can engage in semi skilled or unskilled job.
- **Self- Direction:** One initiates most often own activity, pays attention to task and assumes responsibility.

Potentials of Individuals with Moderate Mental Retardation

Moderately Mentally Retarded Individuals:

They are also considered as trainable mentally retarded children. This child has a very short attention span and memory span and he does not have the mental ability to concentrate. Potentials include:

- **Independent functioning:** One may be able to feed, bathe, dress self, may select clothing, may prepare easy foods for self and others, combs and brushes hair, may oil and shampoo, may wash, iron and store own clothes.
- **Physical:** One may have good body control; good gross and fine motor coordination.
- **Communication:** One may carry on simple conversation, uses simple sentences, recognizes words and signs
- **Social:** One may interact cooperatively and competitively with others.
- **Economic Activity:** One may be sent for shopping with / without notes, makes minor purchases, adds coins with fair accuracy.
- **Occupation:** One may do house hold chores (dusting, dish washing, preparing simple foods that require mixing), may work in a sheltered workshop.
- **Self-direction:** One may initiate most of own activities, attends to tasks.

Potentials of Individuals with Severe and Profound Mental Retardation

They are also considered as custodial mentally retarded. Supervision in daily living throughout adulthood is necessary in this category.

- **Independent living:** One may feed self ,may spill some; puts on clothing but needs help with small buttons and zipper; tries to bathe self but needs help; can wash and dry hands but not very effectively, partially toilet trained but may have accidents
- **Physical:** One may hop or skip, may climb with alternating feet, rides tricycles, may throw ball and hit target.
- **Communication** . One may have speaking vocabulary to make wants known. Understand simple verbal communication including directions

and questions, may recognize advertising words; ice-cream, stop, men, women.

- **Social:** One may participate in group activities and simple group games, interact with others with simple play.
- **Economic Activity:** One may be sent on simple errands and make simple purchases with notes.
- **Occupation:** One may prepare simple foods. Can help with simple household tasks, can set and clear table, may work in a sheltered workshop under supervision.
- **Self-direction:** One may ask if there is work for him to do, may pay attention to task, makes efforts to be dependable and carry out responsibility

1.5 IMPORTANCE OF PARENTING

Parenting is a complex, dynamic process that affects both parent and child. A parent develops and uses the knowledge and skills required to plan for children, give birth to them, and / or rear and care for them (Morrison, 1978).

Parenting is the most essential and enduring profession acknowledged by society, but it is one for which most participants are inadequately prepared. The parents learn the art of parenting as they bring up their children. Needs of the children with mental retardation are not very different from the needs of normal children but the sensitivity in rearing up and understanding their needs is crucial. Parenting such children requires a better understanding of the child's condition, the uniqueness of his developmental pattern and the skills needed in training such children. Invariably parents of such children feel anxious, exhausted and depressed. Such feelings are more due to the 'ignorance' on their part regarding the child's condition and the methods of handling the child, rather than the condition of the child itself. If parents are guided and informed properly at the right time, that is, early in the life of the child, a great amount of strain and stress on the part of the parent can be reduced. Usually parents become aware of the child's problem in preschool years or after he enters the schools, the nature of the disabling condition is mild. If it is moderate or severe, with a conspicuous condition such as in cerebral palsy or microcephaly the parents become aware relatively earlier.

Professionals working in the field of mental retardation are increasingly realizing the necessity to involve families having children with mental retardation early enough in the habilitation programmes. This is precisely for the reason that such an involvement not only helps in strengthening the families but also ensures meaningfulness to the services. In a developing country like India the responsibility for caring and bringing up a child throughout his life talk on the parents and families (NIMH, 1994)

There are many examples nowadays of parental participation in educational programmes, wherein parents have amply demonstrated their competence as 'teachers' and 'tutor'. As Adams (1986) states, "Parents are, first of all, home teachers, parents teach their children the skills of daily living, they serve as models for appropriate behaviour and by listening to and talking with their children they make the most of the environment around them."

1.6 PARENTAL INVOLVEMENT IN TRAINING THEIR CHILDREN WITH MENTAL RETARDATION

Family in India largely has been and still continues to be the basic unit of social security for any citizen irrespective of disability. Trends in the field of mental retardation are changing rapidly. Part of this is due to more attention being given to it and more parents wanting their children to be given equal opportunities in the community and in the schools. Today there is a general awareness of the needs of the children with mental retardation more so than at any other time. More thought is being given to the education and training of these individuals. This is being brought about by local, state, and national parent organization. More stress is being placed 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.

Parents are emphasizing the need for children with mental retardation remaining in school beyond the compulsory age limit of eighteen. More parental organizations are being formed each year in order to help the parents better understand the needs of the children with mental retardation.

1.6.1 Role of Family in Habilitation Process

On suspecting any deficit in the child, parents should immediately seek professional help. They should provide sustained emotional environment where the child can experience affection, friendship and acceptance. They should not give any opportunity to the child to become dependent and also is not expected to take too much of responsibility. Family should provide sufficient opportunities for utilizing the energies present in the child. Parents should be counselled to aim at making the child to develop: independence, courage and a sense of personal and social responsibility. Habilitation and rehabilitation are necessary in the life of a person with disability.

1.6.2 Parents as Partners in Education

Raising children is one of the most demanding activities of adults in families. It involves time and energy in shaping psychological, emotional and cognitive development. Also, it involves many variables ranging from parent-child attachment, previous modeling experiences, and environment conditions that encourage and allow a positive parent-child relationship.

Parents are their child's first and most influential teachers. What parents do to help the child learn is more important to academic success than how well off the family is. Parent's involvement in education programme of the school helps children learn more effectively. Partnership between home and school is crucial. This dictates that parents be active participants and real partner in the process. It is interesting to observe how the pendulum has been swinging in the western countries as to how the professionals viewed the parents. Earlier parents were considered as part of the solution and concerted efforts are being made, now, to involve the parents in the training and management of their persons with mental retardation.

Abram's and Kaslow (1977) stated that a family may contribute, either directly or indirectly, to a child's psychologically caused severe learning disabilities as well as other exceptionalities related to environmental and interpersonal factors.

Vogel and Bell (1960) cited several family factors that may affect the child's learning:

1. Tension and Conflict in the home that inhibits the child's concentration.
2. Parents' and other family members' values and attitudes toward the child and his or her exceptionality.
3. Financial and emotional stress in the family caused by the exceptionality.
4. Criticism and antagonism toward the child or casting the child as family scapegoat.

The specific effects the child will have on the family depends on the family's style, size, composition, resources, as well as the exceptional child's characteristics and other factors. Hammer (1972), recognized six periods of stress in the lives of families with exceptional children:

1. At birth or upon suspicion of the handicap.
2. At time of diagnosis and treatment of the handicapping conditions.
3. As the child nears puberty.
4. As the child nears the age of vocational planning.
5. As parents age and the child may outlive them.

(Hammer 1972, Marion 1981)

1.7.0 THE IMPORTANCE OF EARLY INTERVENTION

It is a known fact that effects of intervention on children with disability and handicap or at – risk can be minimized or prevented if children can be identified early and helped through "Early Intervention" programs. Thus early intervention programmes can be: preventive, creative and remedial.

It is well known that "if you are slow, you simply have to start earlier." There are certain numbers of tasks that have to be mastered in the course of development. As these children are slow in mastering them, they must begin sooner in order to accomplish the ultimate task by the end of the developmental period. The basic aims and objectives of an early intervention program remain as:

1. Acceleration of rate of development in the child.
2. Acquisition of new behaviours / skills by the child.
3. Increase Independent functioning of the child
4. Minimize the effects of handicapping condition

5. Early detection and prevention of secondary handicaps.
6. Render assistance to parents in coping skills and understanding their child better.

It is therefore that early intervention and stimulation in the lives of these children are important.

1.8.0 FAMILY INTERVENTION PROCESS

Families having children with mental retardation have life long reality problem with which they must learn to cope. Sometimes it becomes difficult and even beyond the control to cope up with the stressful situations that ultimately affects the stability of the family life. Family faces many emotional, social, and financial crisis and thus intervention becomes necessary. Family intervention is a method by which a professional tries to enable the family to solve problems situation with stability. Family intervention process can be described through three major stages.

1. **Beginning Stage:** Initially professional tries to establish rapport with the family to ascertain facts related to problem. It is an introductory and exploratory stage where the professional tries to familiarize with the trends and personalities in the family, how the family views the problems situation.
2. **Diagnostic Stage:** Here the investigator tries to analyze the facts gathered during the initial interviews, evaluates family dynamics, explores alternatives by selecting appropriate methods to help the family to regain strength to adjust to situation.
3. **Winding up stage:** This is the final stage where both client and helper are equally active. The client should be able to transfer from a stage of dependency to independence and withstand challenges.

If there is no intervention, the family continues to have stress that leads to severe pathology in the family functioning. Timely help and intervention enhances family's strength to cope up with the crisis situation.

1.8.1 Importance of Need Based Interventions

Understanding how the nature of needs of parents having children with mental retardation change over time would enable service providers to provide appropriate support services to each family member. Research and experience has indicated that approaches which focus on meeting needs of all members of the family are more effective in helping the family to cope with the situation than approaches that focus only on the child with mental retardation. Identifying and supporting the parents in their efforts to meet the needs of all the family members is one of the most efficient ways of developing parental skills which can enhance the development of all family members.

Interventions with parents of children with mental retardation result in parenting, family and child outcomes. It helps in enhancing child development, reducing stress in the family, increasing family coping and leads to improving relationships within the family. For strengthening the families having children with mental retardation, the interventions need to be directed both towards meeting the needs of the index child of parents, siblings and extended family members and also recognize, promote and utilize the existing strengths of the families. (Peshawaria et al., 1995)

Interventions with the families must be based upon a thorough understanding on the factors which effect the functioning of families having a child with disability. It is well understood that:

- ❖ Families both affect and are affected by their disabled members in various ways (Mink and Nihira, 1987).
- ❖ An intervention with any member is in fact an intervention with the whole family (Berger and Foster, 1986).
- ❖ Interventions with an individual disregarding the family functioning may result in an increase in the problems experienced by the family as a whole (Chilman, Nunnally and Cox, 1988).

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 (Hornby, 1994). Consequently, any events or changes that affect one

member of the family will directly or indirectly affect all other members and therefore affect the family as a whole (Marshak and Seligman, 1993). Research and experience in working with families have repeatedly stressed that unmet needs may not only have negative effects on the health and well being of the family, but also interfere significantly in the implementation of the intervention programme. Thus, 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 guide family members in utilizing these identified sources.

In order to make the services more meaningful for families having children with mental retardation, it is logical that services must match the needs of the service users. Assessment of the family needs thus becomes crucial.

Identifying and meeting individual needs of various members in the family is the only way to strengthen the family having a child with mental retardation. Beyond the typical needs experienced by siblings with the birth of a brother or sister, increased stress and additional needs for support are experienced by siblings having brothers or sisters with disability. Thus, to strengthen families having individuals with mental retardation, interventions must recognize the feelings and needs of the siblings (Turnbull and Turnbull, 1990).

1.8.2 Advantages of Parent – Intervention Programme

Parent intervention programme has a positive effect on children's academic achievement, as well as other achievement and increasing their chances of success in life. Parent involvement significantly increases the number of people available to foster the child's development, and the availability of more individualized instruction increases the time the child can devote to learning.

- ❖ As parents' training changes their behaviour towards the child, the child's behaviour may also change positively. Children learn from their parents and siblings in the home (Kelly, 1973).
- ❖ As they are involved in the child's day-to-day activities, they are in a better position to train the children in those activities.

- ❖ 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.
- ❖ Parents training early in the child's life enable parents to teach at home the pre-requisite and readiness skills needed for schooling success.
- ❖ Active parent interest and involvement can boost the child's self-image, which in turn increases feelings of security at home and in school.
- ❖ Involvement in their child's education helps parents fulfill their social and ethical duties to help the child develop as fully as possible.
- ❖ Parent education increases the parents' competence as the child's primary teachers in the home. Parents learn effective instructional and behaviour management techniques and productive communication skills.
- ❖ Parent involvement may reduce personal and family problem related to the exceptional child's difficulties.
- ❖ Parents concern and caring may prevent them from becoming handicap.

Because parents develop an understanding and actively participate in bringing up the child, they accept the child better.

Above all, it reduces the dependence of the parents on a professional for training and management of their child. Parents will be able to independently handle the child for various skill development, once they learn the "know how" of it.

1.9.0 PARENTAL NEEDS AND WAYS TO COPE UP

Common parent concerns about their child's development are on social development, physical health, emotional stability, educational and vocational preparation and capacity for independent functioning in the community.

During these periods, parents need understanding and support, coupled with information and facts. They need to participate actively in planning habilitation for their child and to understand their role in furthering their child's development. Parents also need to maintain their identities as competent individuals and as parents and participating members of the community. And

they need to understand their role in developing positive and realistic expectation for their child.

The greatest single need of parents of children with mental retardation constructive professional counselling 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.

Murray (1959) suggested six basic areas in which parents benefit from professional help:

1. Accepting that the child is exceptional.
2. Handling the life long financial problems accompanying the birth and diagnosis of an exceptional child.
3. Coping with the emotional tension of living with an exceptional child.
4. Confronting and resolving the theological issues raised by the tragedy of exceptionality.
5. Facing and preparing for life time care for the child, even after the parents' death.
6. Handling the frustrations of receiving inept, inaccurate, or ill-timed advice from insensitive or poorly trained professionals.

The child with mental retardation creates additional needs for parents. A need is something that is desired or lacking but wanted or required to achieve a goal or attain a particular end. Research has indicated that greater the number of needs unrelated to child level interventions, greater was the probability that parents revealed that they didn't have the time, energy, or personal investment to carry out the intervention prescribed for their child (Dunst and Leet, 1987; Dunst, Vance and Cooper, 1986).

Following are the common felt needs of the parents of the children with mental retardation.

1.9.1 Behavioural Problem of the Children with Mental Retardation

Presence of behaviour problems is known to produce great amount of stress and management difficulties to parents and other family members. Due to the presence of behaviour 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. Individuals with mental retardation may also find difficult to retain jobs or adjust to work setting if problem persist. No wonder controlling problem behaviour is a priority for many a parents. Parents have been found to benefit a lot from training programmes that help them to become better behaviour modifiers of their own children. 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, etc. The stress on the family members tends to increase with the presence of behaviour problems in mentally handicapped person (Byrne and Cuninghame, 1985). They impose extra care taking demands and burden parents, interfere in their educational process reduce their social acceptability and may also result in the threat of harm to themselves or others (Kaufmann, 1985).

WAYS TO COPE UP: Brockway (1974) integrated didactic presentations, role-playing activities and home assignments into a ten-week behaviour modification course for small groups of parents. Course content includes learning theory, positive and negative reinforcements, rules for behaviour change and changing inappropriate behaviour. Following are some behaviour modification techniques, which have been frequently and effectively used for managing problem behaviours in children.

- I. Changing the Antecedents
- II. Extinction / Ignoring
- III. Time out
- IV. Physical restraint
- V. Response cost
- VI. Restitution (Over correction)
- VII. Conveying displeasure
- VIII. Graduated Exposure for fears
- IX. Differential reward techniques
- X. Self management techniques

Thus, it is important for the service providers to know what are the various behaviour problems posed by persons with mental retardation to their parents for which they seek professional help

1.9.2 Emotional Needs of Parents

No parent is ever prepared to accept the verdict that his child is mentally retarded. The birth of a child with mental retardation is a traumatic experience for every parent. In a child-centered culture such as ours, the meaning of parenthood has deep ego significance. The questions that immediately arise in the minds of the parents are: 1) Of all the children born into the world, why did we have to have a retarded child? 2) Whose fault was it? 3) What did we do or not do that we should have a child like this? 4) Where can we go for help? 5) What shall we do first? 6) What about institutions for the mentally retarded? How much do they charge? 7) Will they become independent in their daily living skills?

These are just a few of questions the parents ask.

Today parents are not isolated. They find comfort in knowing that there are many other parents facing the same problem as they are. They find great relief in talking about their worries, frustrations, and problems with parents who have had similar experiences. The parents must realize that children with mental retardation need to be accepted as they are; they need to be loved for what they are; and they need to be approved by others for whatever contribution they can make to society and the community (Hutt and Gibby, 1968). Marital harmony gets disturbed owing to various child related reasons such as meeting extra-child care responsibilities and burden, affecting sexual relationships between parents due to less privacy, more fatigue and fear of producing another child with disability.

There are certain expressive aspects of parenting an exceptional child

Initial Crisis Reaction:

Human beings react dramatically to a crisis (Webster, 1977). He suggested that the parents of exceptional children experience more crises than other parents over a long period, for they must find appropriate medical care, therapeutic services, education and training programmes, social acceptance for the child, residential care, and recreational services at every stage of their child's development (McDowell, 1976). He suggested that parent's progress through six emotional stages upon discovering their child's exceptionality: disbelief, guilt, rejection shame, denial and a feeling of helplessness. The last

phase, a feeling of helplessness, frequently leads parents to action, at which point they often seek professional help.

Though reactions to the birth or diagnosis of an exceptional child vary from parent to parent and from family to family, people seem to share common elements. Frequently, parents' initial feelings are shock and numbness. Parents may experience periods of panic, anxiety, and helplessness, as well as periods of indifference and anger, at which time parents face nearly overwhelming, depression, apathy, and bitterness.

Mourning and Sorrow:

Parents feel extreme unhappiness upon facing their child's exceptionality. In mourning, parents may express despair and show typical grief reactions, such as weeping, sighing, withdrawal, and so on. It may also include increased irritability, loss of appetite, insomnia, and anger (Prescott and Iselin, 1978).

Denial:

Another typical defensive response is to deny a child's exceptionality; parents may wrongly reason that denying the exceptionality will make it go away so that they need not deal with it. Such denial is a natural response to the crisis – the urge to avoid a painful reality. Parents' denial of their children's exceptionality may take several forms: seeking opinions from several specialists in an effort to find a more acceptable diagnosis; participating in new, unusual, or unproved treatments; overprotecting and sheltering the child; or establishing unattainable expectations for the child.

Avoidance and Rejection:

Prescott and Iselin (1978) suggested that parents avoid and reject their exceptional children in three ways: First, they may set unrealistic goals for the child, making them either overly ambitious or not ambitious enough. Second, they may escape by abandoning the child. Finally, they may act or talk in ways inappropriate for the circumstances of their child's birth or diagnosis

Guilt:

Because of society's expectations, their own expectations, the reality of the child's exceptionality, parents may believe the exceptionality in their fault. They may feel guilt and shame. Some parents become convinced that they did something wrong (Sonnen schein 1981) and scrutinize their pasts for an event or genetic influence on which to affix blame.

Anger and Hostility:

Parents of exceptional children with mental retardation may feel hostile and on occasions, express overt anger towards others (Gordon 1976). The target of parents' anger may be doctor, nurse, social worker, teacher, relative, neighbour or a person who simply asks questions about the child. They resent the time, social and financial burden imposed on them. They may become bitter when they see the child as interfering with personal, family and social goals.

Self- Doubt:

Parents may express their self – doubt as feelings of helplessness. Parents who feel inferior and inadequate may become dependent on others, helpless to make even minor decisions about their children.

Withdrawal and Depression:

Parents may react to their child's exceptionality by withdrawing, almost as if they hope that sufficient thought and time away from the problem will yield a solution.

Embarrassment and Social Isolation:

Some parents are embarrassed by their children and become uncomfortable when people look, comment, or ask questions about the child. Turnbull and Blancher (1980) suggested that parents of mainstreamed children with mental retardation face a daily reminder of the differences between their child and the normal children with whom they attend school.

COPING BEHAVIOURS: After a period of coming to terms with their feelings about parenting an exceptional child, parents begin to "think and behave

constructively thereby facilitating development of the child’s human potential. When the parents are no longer focusing on the disability, but rather on their child as person adaptive and capable of compensating, a new, more flexible, and nourishing relationship develops”.

Acceptance:

Generally, self-acceptance as parents of a child with mental retardation is difficult for most people and parents may feel considerable frustration and self-doubt. According to one study, mothers who develop healthy self-acceptance generally have two major sources of strength: existing ego strength and self-confidence and a commitment to a set of supporting values, such as strong religious beliefs (Gallagher, Cross, and Scharfman 1981).

Love and Hope:

As their crisis reactions lessen and parents become more accepting, they see more reasons to feel good about themselves and their special child (Marcus 1977). Parents develop faith that they, with others, can and will help their special child reach his or her fullest potential. They become confident that they will locate the professionals, services, facilities, and other support systems they need to further their child’s development. They learn to overcome their occasional feelings of anger, frustrations and discouragement.

Parents who have struggled successfully with the personal and practical problems raised by their child’s exceptionality become an excellent resource for other children suffering from disability, their parents, and families. Parents are empathetic. They not only know the facts of exceptionality but they also know how it feels.

COPING RESOURCES:

Internal resources

- Faith in god
- Energy
- Self-determination
- Problem solving skills
- Faith in religion

External resources

- Community acceptance
- Strong extended family
- Supportive partner
- Close friends and relatives

To cope with these emotional traumas yoga gives strength to face it.

Yoga Sadhana is important for freeing the mind of various psychogenic condition and diseases. Children with mental retardation can also be treated up to a great extent with the help of yogic techniques. This may also become very useful for family members. Thus parental training is necessary. With the help of asanas, memory, concentration, learning power, curiosity to learn and the way of thinking are improved. The brain gets more blood supply, which improves mental sub normality I.Q. and social adaptability. Tranquility of mind and diminishing of hyperkinetic behaviour can be increased.

Yogic asanas not only tone up the muscles but it also tones up all the involuntary organs of the body. It improves the individual physical skills and basic controls. Right spiritual approach taught in a practical way to the family members bestowed with the mentally retarded children gives a big support in the management.

Thus yoga as a therapy provides a new insight in the field of mental retardation.

1.9.3 Activities of Daily Living Skill Training to the Children

All parents go through the pressures of bringing up and caring for the child. Such pressures even if the child is normal are more during the early years of child's life as the child is yet dependent on the family for meeting some of his/her basic needs such as toileting, feeding, dressing, self grooming etc. Parents happily bear such problems knowing well that very soon the child will become independent in meeting his self-care needs.

Due to their mental handicap, individuals with mental retardation often lack many thinking tools and observation skills that help to learn even some of the basic daily routine activities. Given such a situation, it is important that individuals with mental retardation be given training in basic self-care at the earliest.

WAYS TO COPE UP: With appropriate interventions, most individuals with mental retardation can learn at least some basic self-care skills like eating, toileting, bathing, dressing etc. Although 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. Therefore, it is very 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. The activities in which these children are to be trained for independent living are very many. Among them, feeding, toileting, brushing, grooming, bathing, dressing are some of the basic and important skills.

Bathing Skills:

Responsibility lies with the parents to lead their children with mental retardation towards independence by giving them the opportunity to learn. Independence in bathing gives a person with mental retardation:

- ❖ Awareness of privacy
- ❖ Self satisfaction
- ❖ Sense of cleanliness
- ❖ Sense of achievement
- ❖ Personal Independence

Dressing Skills:

Dressing is one of the important skills of daily living that needs to be developed to become an acceptable member of the society. Unless proper training is given and children are motivated, they continue their dependence on others.

Feeding Skills:

As the child grows, appropriate meal time skills are needed to become an acceptable person in the society. So independence in eating is a self care as well as a social skill. There is a tendency among parents to feed instead of training the mentally retarded child to eat by himself. It prevents him from achieving eating skills

Toilet Training:

Appropriate toilet habits are one of the earliest skills imparted to a child as this reduces the dependence of the child on parents to a very great extent.

By training the child in toilet habits, the parents are relieved from the task of constant washing of soiled clothes.

Grooming Skills:

Grooming skills are necessary not only for social acceptance but also for leading a healthy life. To keep self neat and odourless and presentable, the skills of using cosmetics is necessary. Maintaining a well-groomed appearance is an art in itself. In case of mentally retarded children these skills are to be taught in a systematic way. By creating an awareness of grooming among the retarded children, they can be made to look as good as others.

Brushing Skills:

The amount of gum disease is much greater in person with mental retardation and is due to poor oral hygiene. Common problems reported by parents of children with mental retardation during brushing teeth are:

- ❖ Difficulty to spit.
- ❖ Habit of swallowing paste.
- ❖ Inability to reach the back of teeth.
- ❖ Lack of initiation or refusal to brush teeth.

To use the right procedures for brushing teeth generally circular motions are recommended as it looses the less enamel with proper training by the parents.

Academic Skill Training:

Depending upon the level of mental retardation, the curriculum for academic skill is determined. The aim of training in academics is to train children with mental retardation in functional academics handle money correctly, commute independently, conduct minor business transactions like shopping, transactions in banks, post offices etc. Persons with mental retardation have to be prepared for responsibilities in adult life. The intellectual capabilities of children with mental retardation are deficient in comparison with their non-retarded peers. The greater the severity of retardation, the greater the deficit in intelligence and hence the greater the problems in learning. Poor

learning and memory functioning in children with mental retardation has been attributed to many factors like:

- ❖ Poor ability to focus on the relevant event in a learning situation.
- ❖ Poor ability to transfer learning from one situation to another.
- ❖ Poor ability to benefit from incidental learning.
- ❖ Poorly developed central nervous system.

Parents want the child to develop a style of behaviour that will lead to the generation of adequate responses to social, personal, and occupational situations. All this has the basic aim of developing as much self-sufficiency in the child as possible.

A good function-oriented curriculum should include: activities that are age appropriate, community referenced, comprehensive, future referenced, efficient, and integrated. According to Baine (1986), the curriculum should incorporate the instructions of motor, sensory, communications, social, personal and self help skills into activities that are functional in the learner's natural environments, including his home, school, recreational and vocational settings. The inclusion of academic skills in the curriculum such as reading, writing, and arithmetic must be absolutely function-oriented and that the person with mental retardation is able to use what is learnt in his daily living. In addition to academic, self-care and communication skills, the curriculum should provide for recreational skills, home management skills, health and safety and community-oriented skills, which contribute to social competence

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

Prevocational Skill Training:

Prevocational training helps in developing individual's personality from being a student to a worker. There are certain skills and behaviour that are essential for any of vocation.

- (a) Cognitive skills. e.g. reading, arithmetic, time and money concept
- (b) Personal skills. e.g. self help skills of eating, dressing, toileting etc

- (c) Social skills: He should be aware of community facilities and how to use them e.g. post office, hospitals, bank etc.
- (d) Safety skills: He should be able to read basic signs e.g. Danger, caution, traffic signals, no smoking etc.
- (e) Work related skills: Individual should be punctual in attendance and regularity.

Prevocational training is part of a total rehabilitation programme whose goal is to develop optimum personality, potential and functions of the individual through treatment and training.

1.9.4 Need for Vocational Rehabilitation

A parent is worth 10,000 masters (Chinese proverb). The single most critical factor in vocational rehabilitation is the support and attitude of the family. Supportive family members like parents, siblings, and grand parents can help in job identification, help improve work habits and be a major source of accurate information about the person's interests and capabilities. Lot of parent organizations in our country is creating vocational training centres for their children.

Vocational Rehabilitation Centres were created by Government of India to provide people with disabilities the opportunity to become employed and therefore to enhance their self identity and their contribution to society.

The goal of VRC's is to serve all types of disabilities; they typically serve individuals with mild mental retardation who have the highest potential for open employment.

VRC's provide a wide array of services like:

- ❖ Evaluation of every client to determine eligibility conditions.
- ❖ Guidance and counseling services through personal contact with a counselor.
- ❖ Vocational training and work adjustment programmes.
- ❖ Placement in suitable employment.
- ❖ Post employment services.

The determination on the part of the parents to treat their children with mental retardation the same way as any other child is the beginning of the process of normalization. The parents need to develop more patience to train their children with mental retardation in simple habits of self-help skills. The need for making families aware of the factor inhibiting their role of parenting they should be helped in coping up with these problem so that they can help the children in growing up. These factors emphasis that for an intervention programme, it is essential to understand the specific need of each family member and on the basis of which the intervention programme can be effectively designed for implementation.

1.10 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 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.

1.11 RATIONALE OF THE STUDY

The presence of a child with mental retardation in the family calls for a lot of adjustment on the part of the parents and the family members. The

concept of family centered intervention reflects that children's functioning can be maximized by providing services that are designed to enhance the effectiveness of their families. Research and experience in working with families have repeatedly stressed that unmet needs may not only have negative effects on the health and wellbeing of the family, but also interfere significantly in the implementation of the intervention programme. Thus to enhance the effectiveness of the family, it is important to identify the needs of individual family members, locate resources for meeting those needs. It is widely assumed that involving parents will effect changes in the child directly as a result of enhancing parental management skills or indirectly improving family functioning through support and counseling. There are the parents of the children with mental retardation who experience great difficulties in their management and treatment because of a lack of knowledge concerning the effect of lowered intellectual capacities upon behaviour in general. 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. There are parents who exert pressures upon the child to force him to perform at levels that are really beyond his capacities of achievement. The parents of children with mental retardation need a great deal of information about subjects as aetiology, management and other services. Parent training programmes help in making parents more independent leading to less dependence on follow-up services with professionals and reduce burden. There is an urgent need to develop model of care, which are cost effective in terms of professional time and money. No work with the children with mental retardation could succeed, if their parents are not involved. It is important to understand them and their emotional difficulties. They should be helped to overcome or at least minimize their difficulties. They should be guided in ways of helping to overcome specific problems of their child. An intervention with any member is in fact an intervention with the whole family (Berger and Foster, 1986). 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 dressing, self-grooming, toileting, brushing teeth, occurs naturally in the home situations 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. Parents may know about the importance of teaching in self-help skills to their child, and know different techniques to teach skills. 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. Unfortunately, though literature is appearing now in India, but it is mostly concerned with the mentally deficient as a whole and not with the problems 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. However each programme evolved is not essentially need based. Therefore while attempting to evolve intervention programme one would first have to, take into consideration the needs of the family for whom the intervention programme is being designed. Some studies illustrated that parents made better gains in the areas of skill training, behaviour modifications, language and speech training etc. 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.

This study is expected to throw light on the various aspects of one of the most important issues in special education, that is, parental involvement. Effectiveness of a programme depends to a great extent on parents' cooperation and involvement. And the present study tries to assess the needs of the parents of children with mental retardation and an attempt has been made to develop the intervention programme and see its effectiveness. The findings of the study may give direction for further research in this area

1.12 STATEMENT OF THE PROBLEM

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

1.13 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.

1.14 EXPLANATION OF THE TERMS

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

Effectiveness: It refers to the amount of learning that is purportedly 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 was seen by comparing pre-test and post-test scores and also by follow-up techniques (through observations, anecdote, field diaries).

Intervention Programme: An approach designed to modify 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 (Grossman, 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.

1.15 DELIMITATIONS OF THE STUDY

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