

**A REVIEW  
OF  
RELATED LITERATURE**

## **CHAPTER – II**

### **A REVIEW OF RELATED LITERATURE**

#### **2.0 INTRODUCTION**

Without a systematic search and critical reading of the literature, it would be very difficult to see how academic research could make a new application of a methodology or contribute in some way, no matter how small, the knowledge may be. Review synthesizes and gains a new perspective, identifies relationships between ideas and theory to application. The major purpose of reviewing the literature is to determine what has already been done that relates to one's problem. Another important function of review is that it points out research strategies and specific procedures and measuring instruments that have not been found to be productive, in investigating one's problem.

In India, research in the field of mental retardation, is of recent origin. Consequently, research publications in this field are very limited. A few reviews of Indian studies are referred here and most of the reviews reported are of studies conducted abroad.

#### **2.1 RELATED STUDIES**

An abstract of relevant researches is presented here under appropriate heads.

##### **2.1.1 Family involvement**

###### **2.1.1.1 Impact on family**

###### **2.1.1.2 Role of other members of family**

##### **2.1.2 Parental perceptions and attitudes towards their child with mental retardation**

##### **2.1.3 Training programmes**

#### **2.2 Implications for the present study**

##### **2.1.1 Need for Family Involvement**

Now there is a great deal of emphasis in all fields of special education, especially in the area of mental retardation and on parental involvement. The literature in special education regularly cites the need for parent involvement

(Epstein, 1987; Turnbull, 1983). It pointed to the need of providing parents with some understanding of the nature of their children's problems and indicated the importance of sharing educational and treatment methods and goals. According to Turnbull and Turnbull (1982), parent involvement in educational programme of their children with mental retardation may be a benefit to some parents and a detriment to others as all parents were not suited to such general educational programmes. Turnbull pointed out the need to individualize programmes for parents as well as their exceptional children.

The Portage Project in rural Wisconsin serves approximately 150 children (0 to 6 years old) who exhibit significantly delayed development in the areas of motor, self help, social, language or cognitive behaviour, by providing home teachers who instruct parents in parenting and teaching techniques. Home teachers developed an individualized curriculum based on the 'Portage Guide to Early Education, and work with parents and their child for 1 ½ hours each week. Parent involvement is one of the most significant aspects of the Portage Project and results in practical advantages such as that of ensuring that the child will do practice every day and be reinforced daily for his / her progress. Data showed that the children achieved a 13 months gain in mental age during 8 months time period and that community support for the programme is growing (Richard, 1974).

Gath (1977) studied on family factors in the development of Behaviour disorders in retarded children. Data were collected, using interviews and rating scales with the parents and teachers of 192 children with Down's syndrome and 147 children with other varieties of retardation but with similar verbal and motor ability. Behaviour disorders were more often found in the children with less adaptive behaviour, poor language skills and evidence of brain pathology whereas social class, sib ship size, maternal age and education had no demonstrable effect on the frequency of behaviour disorders. Behaviour disorders were more common in the retarded children where there were severe psychiatric disorders in the parents, poor marital relationship or disorder in the sibling closest in age. There was no clear association between the frequency of behaviour disorders in the retarded children and the social class distribution of the parents based on the father's occupation. There was no overall effect of maternal age at birth on the behaviour disorders of the children, with the

exception of the mothers who were under 20 at the time they gave birth. The level of a mother's education had no effect on the frequency of behaviour disorders. There was an association of disorder in the retarded children with the quality of the parents' marriages, with behaviour disorders in both groups being more common in the less harmonious marriages. The sibling, either older or younger but closest in age to each retarded child, was assessed using the Ratter Behavioural Rating Scales. There was some relationship between behaviour disorders in a sibling and in the retarded child in the Down's Syndrome group only.

One of the major developments in mental handicap has concerned the inclusion of parents in the teaching and training of their children. In a number of studies mothers attended a centre for training (Connolly et al., 1980; Piper and Pless, 1980), in others they were visited and trained at home. (Cunningham et al., 1982).

Drew, Logan and Hardman (1984) reported that parents expressed needs relating to information about diagnosis, future planning of the child with handicap, medical and financial help. Beveridge (1982) reported that common needs expressed by parents were information on diagnosis and prognosis future planning, aids and appliances, and training technology to facilitate child development. Shea and Bauer (1985) indicated that needs of parents pertained to information on diagnosis, vocational concerns, financial help and future planning of the child with mental retardation

Hanline and Halvorsen (1989) studied the parent perspectives on support services and involvement activities. Concerns regarding the integration, transition, and perceptions of the effects of integration for their child and family. Findings of the study revealed that parents recognized the benefits of integration and see no major disadvantages, although parents did identify areas of concern, the child's staff and nondisabled students, and the success and quality of the student's educational programme. They consistently expressed satisfaction regarding the outcomes of integrating their child, including professional and personal support. In addition, positive outcomes identified by parents such as enhanced learning opportunities, friendships with non-disabled peers, and increased parental expectations.

**D'amato and Yoshida (1991)** conducted a study that was designed to determine, prioritize, and compare the informational needs of parents at different stages in the educational life cycle of their son or daughter with a handicapping condition. Forty pairs of parents who had a child with mental retardation between three weeks and 12 years old were included in the study. Findings of the study revealed that child's lack of speech appeared to be more difficult for parents during the preschool years. Behaviour problems, appeared to become increasingly more difficult for these parents as their child matured and continued to require close supervision and management. Areas of desired development identified by parents of children between 6 and 12 years of age included speech improvement (30%), self-help independence (25%), and gross motor proficiency (20%). Although these children were verbal, their parents wanted to see improvement in the quality and quantity of their speech. A number of parents would also like to see their children become more agile and acquire such recreational skills as pedaling a bicycle and playing basketball.

**Peshawaria et al., (1991)** in their study included the first three hundred cases of persons with mental retardation reported behaviour problem registered at NIMH during the years 1987 – 88. The parental needs with regard to behaviour problems in their children with mental retardation were analysed in twelve areas, viz., physical harm towards others, damages property, misbehaviour with others, temper tantrums, wandering, disobedience, repetitive behaviours, self injurious behaviour, restlessness, physical overactive behaviour decrease with age. In terms of family variable, it appeared that, both, parents from nuclear as well as non-nuclear families perceive "disobedience" as the major behaviour problem in their children with mental retardation. Trends in parental perceptions of behaviour problems in children with mental retardation significantly highlighted the need for professionals working with this population to equip themselves with skills to identify such problems early and help parents to manage them promptly.

A study conducted by **Minikutty (1993)** on the perceptions of teachers on involvement of parents in the education and training of mildly and moderately mentally retarded children and revealed that: (a) the existing level of parental involvement in developing self help skills, number concept, time concept, domestic skills and vocational skills in mildly mentally retarded

children and the level of involvement as supporters is very low; whereas teachers perceived a higher existing level of parental involvement in developing communication skills and social skills.

The involvement of families with a child who has mental retardation in residential placement was studied by **Baker and Blacher in 1994**. Sixty-two families who had placed their child out of the home within the previous 2 years were interviewed about behavioural and emotional aspects of involvement. Involvement was high with 81% of families having at least a monthly visit with their children. There was only marginal evidence for detachment, a lessening of involvement over these two years. Although family involvement related to several child and family characteristics the strongest relation was with placement facility characteristics, especially opportunities for involvement in the facility. Correlational analyses was used to examine the interrelations among the family involvement variables and multiple regression analyses was employed to determine the set of independent variables that best predicts each behavioural involvement variable.

**Grover (1995)** conducted a study on reported networking of social supports by parents of children with mental retardation. For the training and management of child with mental retardation the advantages of family centered intervention over child-centered intervention are widely known. Effective family centered interventions dependent upon the relationship of the family members with their social network members. This was an empirical study, in which parents were interviewed. The data were collected for the three groups viz, family, friends and neighbours and professionals. The available social support was recorded in terms of household, financial, emotional, therapeutics and information. Data were analysed with respect to nature, size and social support available, separately for each parents, having child with various degree of mental retardation. Results indicated that almost 30% of the parents have no network at all outside of their family and relatives. Another area where professional networks important was of therapeutic nature. Here also the network was found to be lacking. Parents expressed varying degree of emotions during the interviews which ranged from resigning to their fate to being very optimistic that their child will compete with normal children. One

major factor that emerged was that most parents would prefer help from professionals rather than family, friends, or neighbours.

**Garshelis and Mc Connell (1993)** reported that mothers' most frequently cited needs were for more information on present and future services, more reading materials about how other mothers cope, more time for themselves and help in locating a babysitter.

**Cram (1999)** investigated the extent to which the family environment predicted differences in trajectories of adaptive development in young children with Down syndrome. The sample comprised of 54 children with Down syndrome and their families who were studied from infancy through the age of 5 years. Hierarchical linear modeling was used to estimate the parameters of hierarchical growth models in domains of adaptive development. Results indicated that growth in communication, daily living skills and socialization domains were predicted by measures of the family environment (i.e., family cohesion and mother – child interaction) above and beyond that predicted by maternal education. Further, Bayley MDI measures during infancy did not predict changes in adaptive development in any of the domains.

**Parette, H; Jane, M; Blake, M (2000)** investigated how professionals could help families learn to use augmentative and alternative communication devices. Parental involvement in parent – professional partnerships was stressed.

A thorough examination of the research studies carried out in this area shows that parental involvement influences communication and socialization domains of the children with mental retardation. Most of the parents expressed needs for prognosis and diagnosis of the children with mental retardation. They were also worried about the future of their children. Need was also felt for the more number of inclusion and integrated schools for these children. Limited numbers of researches have been carried out in India as compared to abroad that deals with these aspects.

#### **2.1.1.1 Impact on Family**

The stress on the family members tends to increase with the presence of behaviour problem in the person with mental retardation (**Byrne and**

**Cunningham, 1985).** They impose extra care taking demands and burden parents (**Bradshaw and Lawton, 1978**), interfere in their educational process (**Mortimore et. al., 1985**) and may also result in the threat of harm to themselves or others (**Kauffman, 1985**).

Some investigators have found that such families have heightened parental stress (e.g., **Dyson and Fewell, 1986; Kazak and Marvin, 1984; McKinney and Peterson, 1987**). Others have reported that these families do not experience greater stress (**Fray, Greenberg, and Fewell, 1989; Gown, Johnson Martin, Goldman, and Applebaum, 1989**) or less marital satisfaction (**Kazak, 1987**).

Researches on the internal coping strategies are very limited. According to **Turn bull and Turn bull (1990)**, the most common internal coping strategies used by parents of children with mental retardation include use of passive appraisal and spiritual support.

The association of the presence of a child with handicaps and parental stress and family dysfunctioning was examined by **Dyson (1991)**. Fifty-five families with young children with handicaps on the variables of parental stress and family functioning were chosen. Results of family psychological measures suggested that families might be resilient in adapting to the demands of raising a child with handicaps. Although families of such children appeared to have high degrees of stress, they differed only minimally from other families in their family functioning. Results provided strong evidence that family stress is related to the care of a child with special needs in a middle class family. Further results suggested that parental stress is especially related to the child with handicaps and concerns such dimensions as parent and family problems associated with care taking, parents' pessimism, and negative view of the child's limitations.

**Venkatesan and Snehlata (1997)** in their study attempted to elicit depressive cognitions by administration of a 45 items self-report **Crandell's Cognitions Inventory** on 62 parents of children with mental retardation. The results showed that fathers are assailed by greater amounts of depressive cognitions than mothers. Respondents hailing from nuclear families having two or more children and / or moderately mentally handicapped male children showed a greater prevalence of depressive cognitions.



Family Interview for Stress and Coping in Mental Retardation (FISC – MR), a semi structured interview schedule, was developed by **Girimaji et al. in 1999**, as a part of two years prospective study of efficacy of brief family intervention for 157 children with mental retardation. The tool consists of 2 sections – one measuring stress (daily care, emotional, social and financial) and the other measuring mediators of stress or coping strategies (awareness, attitudes, expectations, rearing practices and social support). Many instruments were used to collect data at intake and follow up. From the results, it was evident that the new instrument measurably satisfies the requirements of standardization in terms of reliability and validity. Some loss of associations may have occurred in test – retest reliability due to the possibility of intervention acting as a confounding variable. Limitation of the instrument is that it takes approximately 45 min. to administer.

**Roach and Orsmond (1999)** examined parental stress in socio economically matched samples of mothers and fathers of children with Down syndrome and typically developing children. Parents of children with Down syndrome perceived more care giving difficulties, child related stress (distractibility, demanding ness, unacceptability), and parent related stress (incompetence, depression, health problems, role restrictions) than did parents of typically developing children. For the combined groups of parents, mothers stress was associated with children's care giving difficulties; fathers stress, with children group status (down syndrome, typically developing). Mothers who reported more responsibility for childcare perceived more difficulties with health, role restriction and spousal support. Fathers who reported more responsibility for childcare perceived fewer difficulties with attachment and parental competence. Partner stress was associated both with mothers and with fathers.

**Seltzer (2001)** compared parents who had a child with developmental disability, a serious mental health problem and a normative comparison group with respect to parental attainment and well-being at mid life. Data are from the Wisconsin longitudinal study, collected when the respondents were 18, 36 and 53 or 54 of age on average. Parents of a child with a developmental disability had lower rates of employment, larger families, and lower rates of social participation but were similar to parents without a child with a disability, in

educational and marital status, physical health, and psychological well-being. Parents whose child had a mental retardation had normative patterns of educational and occupational attainment and marriage, but elevated levels of physical symptoms, depression and alcohol symptoms at mid life.

In the light of the above, it can be concluded that the families with children having mental retardation remain under constant stress and anxiety. Parents take them as an extra burden on the family. Studies on how the families can cope up with such children have been done to a limited extent. Therefore studies are greatly needed in this area so that parents can be suggested as well as provided with the appropriate coping up strategies in order to deal with such kind of children effectively and thus provides them relief from the anxiety, which they constantly undergo. Studies conducted in this area have been conducted more in abroad.

#### **2.1.1.2 Role of Other Members of Family**

Intervention programmes in India have neglected the contributions that siblings can make to strengthen families having children with mental retardation. Just like parents who have children with mental retardation, siblings having brothers and sisters with mental retardation also need special attention, understanding and support (Powell and Ogle, 1985).

When siblings were given direct responsibility for the care of the handicapped child, they tended to express satisfaction (Chintz, 1981; Schreibman et. al., 1983), particularly when the results of their efforts helped the children with mental retardation.

Studies have also indicated that older female siblings most adversely affected by the presence of a handicapped child because of additional care responsibilities (Cleveland and Miller, 1977; Gath, 1974; Grossman, 1972; Mc Hale et al., 1984).

Sukumaran (1986) found that most of the normal brothers and sisters of children with mental retardation were sympathetic, helpful and understanding and did not seem to be adversely affected. In their study, Auletta and De Rosa (1991) found that siblings of children with mental retardation have no special difficulties in psychosocial adjustment when compared with the siblings of normal children.

**Knott et al., (1995)** conducted a study to test two potentially contrasting hypotheses relating to sibling interaction involving children with autism and Down's syndrome. These hypotheses were that learning disabled children would assume responsive roles in sibling interaction and that autistic child's interactions would be impoverished. Out of the chosen sample of 30 sibling dyads, half contained one child with Down's syndrome and one developmentally normal child. All learning disabled children often interacted with their siblings, usually under sibling directions. Autistic children reciprocated their siblings' initiations but engaged in fewer bouts of interaction and emulated less than children with Down's syndrome. It is concluded that interaction with siblings affords learning disabled children a unique opportunity to learn about social relationships.

**Wolf et al., (1998)** conducted a study to examine sibling perception of parental differential treatment in families of children with Pervasive Developmental Disorder (PDD), Down syndrome (DS) and nondisabled controls. Sibling self-concept and social support were examined, and caretaker and teacher evaluations of sibling behavioural adjustment were studied. Findings revealed that for siblings of pervasive developmental disorder children, internalizing and externalizing behaviour problems identified by caretakers were evident at time one and more accentuated at time two. Siblings of Down syndrome children were reported by caretakers and teachers to have only internalizing problems, and only at time two. These problems related to the perception among PDD siblings that they were preferred over their disabled sibling and for DS siblings that their disabled sibling was preferred.

Grandparents are important sources of support to children with disabilities and their families. The birth of a grandchild with disability can have a variety of adverse reactions on the grandparents. However there have been very little published researches concerned with grandparents' roles and experiences in relation to their grandchild with disabilities.

Research in the West has revealed that the birth of a grandchild with disability evokes different emotions than those produced by the birth of a healthy grandchild (**Meyer and Vadasy, 1986**). Whereas **Hornby and Ashworth (1994)** in their survey of parents of children with severe disabilities

found that there was a low level of support from grandparents. The nature of the social and emotional support that grandparents provide to their own children influences the ability of the parents to cope with the crisis.

**Sandler (1995)** has also reported that Grandparents are a source of support for parents of children with disabilities. A significant positive correlation between paternal adjustment and grandparent support was found. Grandparents' most frequent forms of assistance were baby setting and buying clothing for their grandchildren.

**Hastings (1997)** in his paper reviewed that although both parents and grandparents themselves reported a wide range of supportive activities and increased involvement with the child with disabilities, grandparents may also be an additional burden to families. In particular parents may find it difficult to deal with grandparents' immediate and longer-term emotional responses to their grandchild's disability.

**Seligman et al. (1997)** found that there has been a fair amount of study in the area of family adjustment to childhood disability. Little attention has been given to more peripheral family members, such as grandparents. This study explores the perceptions of mothers (N = 42) of children with disabilities of the amount of instrumental and psychological support offered by her child's maternal and paternal grandparents. The results showed that: grandmothers were perceived to be more supportive than grandfathers, the father's mother were less supportive than the mothers' mother, and the mothers' parents were judged to be more supportive than the fathers' parents.

Few studies were of the view that siblings of children with mental retardation have no problems in psychosocial adjustment and few revealed that siblings are adversely affected by the presence of children with retardation. A few studies have been carried on the grandparents of the children with mental retardation. It was found that grandparents displayed strong emotional reactions towards such children. It became difficult for parents to deal with such situations where grandparents were not understanding the problems of the children with mental retardation

### **2.1.2 Parental Perceptions and Attitudes towards their Child with Mental Retardation**

Parental expectation as well as perception towards the person with mental retardation varies through intervention. Their expectation from the child may influence their involvement in training since early intervention to vocational placement.

Parents of 50 children with mental retardation children were investigated by **Rastogi (1981)** for their attitudes towards their retarded children. Attitudes of father towards his child revealed that majority of fathers have a favourable attitude. The analysis of attitude of mothers towards their children with mental retardation did not show any significant difference. When the attitudes of both the parents toward their child were compared, mothers exhibited significantly higher score on unfavourable dimensions (rejection, aggression, shame and guilt) in the severely retarded child.

**Chaturvedi and Malhotra (1984)** conducted a study on the perception and attitudes of parents of children with mental retardation. Thirty such children were followed up after one year of initial contact and the parents were interviewed. Parents of higher education had a more scientific perception. Most parents had unrealistic hopes and expectation. Feelings of shame, guilt and self blame were predominant. Rejection, hostility, neglect of child and other negative attitudes were significantly more often seen in younger parents, urbanites and those with higher education. The negative attitudes were more towards a child with additional psychiatric problems. Educated parents and those from urban background had a more scientific perception of the condition and its cause.

**Nikapota (1986)** studied the parents' perceptions of needs for the care of their children with mental retardation in Sri Lanka in relation to SES and degree of disability of the child. The results of the study demonstrated that the educational level of parents affected their ability to express specific service need, though educational level did not appear to relate significantly to the type of service requested. Parents are influenced by the availability of residential institutions to more socially competent children. This reinforces parents feeling that they should educate their retarded child as they do their normal child. He suggested that educational programme for parents of retarded children would

help them realize that they could effectively train their child at home to be as social competent as possible.

**Madhavan and Narayan (1992)** studied the impact of professional intervention on the perceptions and expectations of their mentally retarded children in one hundred parents. The perceptions and expectations of parents on their first visit were collected from the case records which were elicited again during follow up visit. The number of follow ups for each case was noted. The data on pre-intervention and post intervention perceptions and expectations were grouped and analysed. The parents had varied perceptions with regard to the condition of their child at the time of their first visit. In certain instances, the perceptions changed with follow up services. It was found that two of the perceptions were significantly altered, namely, the assumption on brain development and cure for mental retardation. None of the parents during their first visit believed that the child could improve, while sixteen of them accepted, after intervention, that the child could. The positive effect of intervention has been reported where it was found that a goal directed parent training approach brings about attitudinal change, family satisfaction and improvement in the child's functioning. The need for training and the need for drugs to control fits also were perceived by considerably more number of parents after interventions. A notable number of literates continued to expect total cure for their children even after intervention. Parent training has been rated as effective means of improving parental perception and promoting positive parent child interactions.

**Tangri and Verma (1993)** studied the impact of the presence of a child with mental retardation and physical handicap on the attitudes and marital adjustment of the parents. Three groups of mothers (Group I of 50 physically handicapped, Group II of 50 mentally handicapped, and Group III of 50 normal children) participated in the study. Data were collected using parental attitude scale and marital adjustment questionnaire. Data revealed a significant higher degree of marital adjustment in the parents of normal children than those of handicapped children. Parents of physically handicapped children had more favourable attitude toward management than the parents of children with mental retardation. The results emphasised an imperative need for more coordinated and systematic preventive measures to help the parents to

readjust successfully to the problems created by child's handicap before the adverse impact had the chance to occur.

**Llew Ellyn (1995)** used qualitative design to explore views of parents with intellectual disability about their relationships and social support for their parenting. Most emphasis was placed on the support received from and given to their spouses or partners. Support was not always beneficial rather, it was sometimes viewed as a restraint as well as a resource for parenting. Parents also exhibited a preferred sequence in seeking help, beginning with their partners, then family members, and, finally, professionals.

**Turn bull and Ruef (1997)** conducted interviews with 17 families of children, youth with problem behaviour (e.g. aggression toward others, property destruction, self-injurious behaviour). Results are organized into categories that emerged from the qualitative analysis, including family life, friendship issues, school issues, and community inclusion. In case of relationship with siblings, the major types of challenges were reported to be lack of a bond or close connection between the person with the problem behaviour and his or her siblings, feelings of resentment about not having a normal brother or sister. The most frequent home routine problem mentioned by the majority of families was their child's difficulty being productively involved in home activities. These problems related to the incessant need of some of these children for parental attention and supervision. Over two-third of the families described the absence of even one friendship for their children with problem behaviour. About teachers' considerations, whether children were placed in special or general education classes, majority of the families believed that many teachers lacked training in providing appropriate instruction and behavioural supports. Several families pointed out the importance of inclusive school experiences as a catalyst for expanded opportunity to participate in the community. Interestingly, when children could participate in the community, then the family could do like wise and avoid being so isolated themselves.

**Peshawaria (1999)** analyzed the perceptions of 50 parents and 76 professionals working with individuals with mental retardation towards marriage of individuals with mental retardation. Responses were obtained for two specific questions

- (i) Whether the individual with mental retardation should get married or not?
- (ii) Reasons for getting them married or not getting them married

The findings revealed that the parents have a more favourable attitude towards marriage of individuals with mental retardation than the professionals. Results also indicated differences in perceptions between parents and professional with regard to reasons in favour and against marriage of mentally retarded individuals with mental retardation.

**Hodapp (1998)** in his study examined how the child's type of mental retardation and current educational placement affect parental educational perceptions. Subjects were 32 mothers of children with Prader - willi syndrome and 32 mothers of children with Down syndrome. Both groups responded to surveys consisting of demographic information, perceptions of current educational placement, and perceptions of ideal educational placement. Although parents of both groups were equally satisfied with current placements yet parents of students with Down syndrome – as well as those now in more inclusive programme were significantly more likely to choose an inclusive placement as their ideal programme. Parents of children with Prader - willi syndrome were significantly more likely to choose curriculum as a disadvantage of their current programme, and less likely to cite teachers and the location of their child's school as disadvantages of their child's current programme

The purpose of **Mutua's (2001)** study was two – fold. First to identify factors that mediate parents' expectations about future outcomes of children with mental retardation and parents' believes about education of children with mental retardation in Kenya. Second, to determine the importance of parents' expectations, believes, child's gender, severity of mental retardation, ethnicity, and parents' level of education in the prediction of educational participation of children with mental retardation in Kenya. The initial set of predictors included four demographic variables (Child's gender, severity, of mental retardation, ethnicity, and parents' level of education) and eight factors of parents' expectations about future outcomes of the child with mental retardation and their beliefs about education of children with mental retardation Six predictors of educational participation of children with mental retardation emerged:



- (i) Parents' beliefs about the educational appropriateness of the child with mental retardation,
- (ii) Parents' beliefs about the social acceptance of the child with mental retardation,
- (iii) Parents' level of education,
- (iv) Importance of school characteristics,
- (v) Parents' beliefs about segregated school option, and
- (vi) Parents' beliefs about worthlessness of education of children with mental retardation.

**Park and Turnbull (2001)** conducted a study on perceptions and experiences of Korean parents of children with special needs with regard to the special education services they have been receiving or seeking in the US. In depth interviews were conducted with eight Korean parents of children with disabilities. Main themes refined from the analysis of the data include (i) parents' satisfaction with special education services in America, (ii) experiences related to exchange of information with professionals (iii) need for a mediator and (iv) parents' perceptions of inclusion.

**Behari (1983)** studied the attitudes of mothers of boys with mental retardation towards 23 areas of child rearing as influenced by their strata and education. The sample in Group I consisted of 30 less educated, low class mothers and Group II comprised 30 well-educated upper – middle class mothers. Results of 't' test indicated that attitude of mothers in Group II were significantly different from those of mothers in Group I on seven areas of child rearing practice, namely, (i) Marital Conflict, (ii) Rejection of home making role, (iii) Ascendancy of the mother, (iv) Dependency of the mother, (v) Intrusiveness, (vi) Approval of activity and (vii) Equalitarianism. Hence it was concluded that it is not strata and education per se which are important in child rearing attitudes but other psychological variables play a crucial role too.

**Mamta and Punia (2003)** conducted a study on the maternal knowledge of mental retardation on the basis of background area, residential area and socio economic status. Parents indicated that parents had high and moderate knowledge regarding the aspects of mental retardation except the facilities provided to the children with mental retardation. The parents of urban areas

were better in knowledge on all aspects than rural parents because urban parents have more exposure to media which help in improvement of their knowledge and conscious about the improvement of their child's condition and also having better educational, and socio economic status. Further it was found that lower socio-economic group parents were poor in their knowledge than middle and high socio-economic group parents.



Studies indicate that education of the parents is instrumental in the formation of attitudes towards their children with mental retardation. Positive attitude is directly associated to higher education. Parents of higher education have more scientific perception. Studies have also shown that intervention programme is useful in changing the attitude and perception of the parents towards their children with mental retardation. Studies have also pointed out the difference in the attitude of mother and father. More studies have been conducted in India as compared to abroad related to this area.

### **2.1.3 Parental Training Programmes**

Though children with mental retardation cannot be made normal, they can certainly be trained to independently look after their activities for daily living. Once the parents will be trained, they will be able to independently handle the child for various skill development, behavioural problems etc. Numbers of researches are done on parental training programmes which are as follows.

General discussion of parent training programmes introduces the report of a clinical programme which teaches parents of developmentally disabled, mentally handicapped, or behaviour problem children to analyze, utilize, implement, and evaluate behaviourally based intervention programmes. Effective training programmes are defined as those in which the parents specify the problems, those that are skill oriented, and those that are responsive to parental needs and abilities. It is suggested that instruction focus on such skills as assessment of behaviour in need of remediation, identification of necessary environmental modifications, and documentation of degrees of behavioural changes. Described is a clinic project which provides parents with sequentially prepared remedial programmes based on the principle of individualized programming which are designed to remediate dysfunctions in daily living skills,

language development, pre-academic and academic skill development, and social adjustment. Each programme is reported to require utilization of positive and negative feedback and the employment (David and Fredericks, 1974).

According to Deanna and Donald (1977) home based early intervention programme for the care of young retarded or children with severely mental retardation are becoming available as an alternative to group care settings. Home visits, parent workshops and remote control parent involvement programmes are some of the types having home based programmes that are being tried. Structuring of the learning situation and the comprehensiveness of the family support system are among key elements of these types of programmes. Enhancement of cognitive and socio emotional growth of children and changed attitudes and behaviour in mothers are some of the advantages of the programmes. Families must be organized and have the ability, time, energy, and willingness to participate in order for home based programme to work.

Heifetz (1977) conducted a study on behavioural training for parents of child with mental retardation. One hundred and sixty families were randomly assigned to four training conditions in behaviour modification (telephone consultations, training groups, training groups plus home visits, and instructional manuals). The 20 week treatment period emphasized the programming of self help skills, but also provided an introduction to programming language skills and managing behaviour problems. The instructional manual was as effective as the more expensive training formats in producing gains in children's self help skills and fostering knowledge of behavioural principles in mothers. The two group training formats produced more efforts at behaviour problem management, greater gains in knowledge of principles by fathers, and higher self confidence as teachers.

Embar (1979) organized a workshop for parents of the mentally retarded. The aim of the workshop was to help parents accept their retarded child, and to find ways of encouraging the development of their child. Each parent's attitude towards rearing of children was assessed before and after 6 weeks of attending the workshop by means of an attitude scale. Each child's social age, and developmental levels were assessed before and after the training, using the social maturity scale. Improvement was observed in all the

developmental skills, except in the area of using language. The improvement was significant in the areas of general social development, feeding, standing and walking, grasping, social and imitative play. Though most parents are willing and interested to learn how to manage their subnormal children, yet there are obvious difficulties encountered, in attending the sessions regularly. Active parental involvement in the training and management of their subnormal children is beneficial both to the parents and the child. There is a change in the attitude of the parents towards their mentally retarded children.

**Baker et al., (1980)** conducted a study on ninety-five families who had completed a 20-week behavioural training programme for parents of retarded children. They were re-contacted 14 months later. An in home interview and several questionnaires assessed maintenance of child gains and parents' knowledge of programming principles, as well as the extent and quality of continued and new programming, perceived obstacles to home teaching, and perceived effects of the training programme. Parents had retained their knowledge of programming principles, and the children had retained their original skill gains. Many families had initiated some teaching of new skills, although few parents carried out regular formal teaching sessions. Almost one-half of the families were classified as having continued to employ useful or very useful teaching. The main perceived obstacles to home-teaching were limitations in time, in the child's learning ability, in the parent's teaching ability, and in professional support.

**Pandit (1987)** assessed the relevance and effect of training rural based parents from Wai taluka to manage and educate their children with mental retardation. Findings of the study revealed that the parents of all rural base children with mental retardation did not accept training for managing and educating their children because their children were dependent upon them in all respects and their inability to appreciate the child's needs. The programme of carrying out management assignments was closely followed by a few parents. Parents' behaviour in relation to their child with mental retardation changed as the programme continued.

**Walker (1987)** in his article reported the effect of a comprehensive job seeking behaviours training programme on the ability of persons with mental retardation to perform the skills required for seeking and obtaining competitive

employment. The audiovisual training programme used was evaluated in a variety of rehabilitation and work activity centers. The programme produced significant improvement in all five training areas, personal care, use of job referral sources, job application completion, nonverbal interview behaviours, and verbal interview behaviours. The results of the study indicated that mentally retarded persons can be taught appropriate job seeking behaviours more effectively with the Job Seeking Behaviours training programme than with traditional individual training methods. In all five training phases, the Job Seeking Behaviours trained persons show significantly more improvement than those using traditional methods. The overall difference between the groups was also significant. The JSB programme was also expected to be equally effective for both males and females due to the variety of teaching materials and methods used. The mildly retarded clients had average pretest scores that were 45% higher than the moderately retarded clients.

Narayan et al., (1988) conducted a novel programme of intervention brief inpatient family intervention which was formulated to impart the training skills to the parents of mentally retarded children to optimize the development of their retarded child. During the period of this study, 106 mentally retarded children with different socio-demographic backgrounds and degrees of handicap participated in this programme, with encouraging results. The individualized management plan, spread over 2 weeks of inpatient stay, included intensive counseling, training of the parents in techniques of multisensory stimulation, speech, motor, and self-help skills training, behaviour modification and medical management. The most important trends emerged from this study were: (i) Most parents experienced a favourable change in motivation to train their child and, (ii) Most children had small gains in their skills during their participation in the programme. These findings could be taken to reflect the efficacy and utility of the approach in general. However, these changes were not significantly related to any of the socio-demographic or clinic variables, though there were some non-significant trends.

Parikh (1989) conducted a study on the life of children with mental retardation at home and the crux of the play center technique, which is the home based programme. The impact of the home based programme was analysed in terms of (a) behavioral change in children, and (b) behavioural

change in their parents as observed after the programme. Results indicated through a need based recreational programme, parents were able to understand the value of providing various recreational experiences at home. Successful channelization of children's potentials through recreation experiences was also seen. Overall behaviour change in the child having mental retardation and their parents was observed after home based programme.

**Holden et al., (1990)** examined the background and observational records of 158 mothers and their children who began a behaviourally oriented training programme for child non-compliance. Clients were from a heterogeneous urban population. The key parent and child characteristics found to be related to completing the programme and to speed of progress through the training were social status, ethnic group, number of presenting problems, and child's age at intake. The dropout group ( $n = 45$ ) was comprised all those who terminated before finishing all four phases of the mother-child dyads who completed training, who finished in the fewest sessions, was designated the rapid completers group; who required the most sessions to complete training, comprised the slow completers group. A step wise multiple regression analysis was conducted to evaluate which variables were associated the most with the number of sessions needed to complete the training. The parent and child characteristics associated with a continuum of effectiveness have been probed for one parent-training programme serving heterogeneous urban population. The mother – child dyads differed by two or three variables at each point on the continuum. A group of mother-child dyads were formed who completed the programme but took a relatively long time to do so. Mothers from the fast completer group tended from a higher socio economic group, with children who were older, had fewer presenting problems, and were more cooperative than those who required more time to complete the training. The data indicated that for this programme, the older children profited from the training more than the younger ones did.

**Rani and Reddy (1990)** conducted a study on Family's Role in the Early Intervention Programmes for the children with mental retardation. The study was taken up in 70 children with mental retardation, which includes 61 children with DS (Down syndrome) and 9 children with non-specific mental retardation.

Results revealed that the progress of the children was good when the mother was deeply involved in the home training programme. In some cases, although mother is keen to train the child, she could not attend the training schedule because of lack of time, non-availability of other family members to help her in training programme or to take up her routine household activities. In very few cases the father was involved in training. Further, it was revealed that when the child is the only child, he / she gets naturally more or rather full attention from the family members and hence the children achieved good progress in their development. In case the child is first born or the middle born the progress is either fair or moderate respectively as the parent's concentration cannot be fully focused on one child.

Group Parent Training Programmes conducted at NIMH have been evaluated by Peshawaria et al., (1991). Each of the programme was conducted for a duration of three days including a total of 157 parents of children with mental retardation. The parents were trained in the areas of nature and medical aspects of mental handicap, speech and language aspects, skill training aspects, and behaviour modification with the persons with mental retardation. Training methods used included didactic lectures, demonstrations, discussions, role-play and group discussions. The pre and posttest results, course feedback questionnaire and open session with parents revealed significant gains made by the parents. Parents after the course generally reported to feel more confident in handling their children. Results from the pre-post questionnaire and course feedback are quite encouraging. Parents seem to have made better gains in the areas of skill training and behaviour modification than in nature and medical aspects and speech and language training.

Upshur (1991) studied on ratings of early intervention services received by 91 mothers and fathers were analyzed one year after entry to programmes in Massachusetts and New Hampshire. While a high level of helpfulness was indicated, service components directed specifically to parents instead of to parents and children together were rated less favourably. In addition, mothers and fathers differed in their ratings, and the weighting of perceived benefits varied by child and family characteristics. This study has demonstrated that though mothers and fathers in this sample were very satisfied with the first year

of early intervention services, much can be learned by soliciting feedback about specific aspects of services. Not all service components were rated as equally helpful, and parents' perceptions of areas of relative programme benefit varied by child and family characteristics. Further, important differences were found in the ratings of various areas of benefits by mothers and fathers and in which study outcomes were associated with ratings of overall service helpfulness.

**Verma et al., (1992)** conducted a study to evaluate a home-care programme for the children with mental retardation through training of the mother and found a significant improvement in the behaviour of the children and in the marital adjustment score, parental attitude and social burden felt by the mothers.

**Thressia Kutty (1993)** presented a paper on parents Associations for Vocational Training and Employment of Persons with Mental Retardation. Parents of nearly 1000 mentally retarded children above 16 years residing in twin cities of Hyderabad and Secunderabad are currently seeking guidance in vocational training and employment. Four Parents Associations have been formed in different parts of Hyderabad and Secunderabad under the professional guidance of NIMH. Awareness was created among various agencies like South Central Railways. Machine Tools and Village Industries to provide services in their campus for the mentally retarded. General observations were made and found that job site training was more effective than centre based training. Parents gained confidence to manage the centre. So they could get maximum output from minimum inputs. The production centre stands as a symbol of appreciation of the abilities of the mentally retarded individuals and the efficiency of the parents, rather than a place of sympathy. Parents can be trained to become effective organizers and service providers under professional guidance with community support.

**Schultz et al., (1993)** conducted a study, which was undertaken to ascertain long-term outcomes of the psycho educational support programme. The aim of the programme is to empower the individual and thereby strengthen family resources the written evaluations of treatment subjects, were employed to examine programme effectiveness. For the fathers and mothers of children with disabilities, psychological health and well-being was assessed on the General Health Questionnaire, using a pretest and follow-up control group



design. Results showed a statistically significant difference between groups, 12 months after treatment, with programme participants displaying less emotional distress than control group subjects. The positive direction of behavioural and attitudinal outcomes, which emerged from evaluation of the small group intervention, was similar for both mothers and fathers.

**Levenson (1994)** found that the parent education course for the parents of children with disabilities as helpful in increasing their parenting skills and decreasing their parental stress. Similarly, the results of the study conducted by Wells (1994) indicated a significant relationship between parent involvement and parent knowledge of special education.

**Repp et al., (1994)** conducted a functional assessment of problem behaviours of 2 students in their classroom environments. Results of the assessments showed that although there were more tantrums in demand than in no-demand conditions, the function of the behaviour was to gain attention (positive reinforcement) rather than to avoid or escape demands (negative reinforcement); demand conditions apparently served a discriminative function for the availability of attention. Therefore, intervention was based on the positive reinforcement hypothesis, resulting in a substantial reduction of tantrums for both subjects.

Study conducted by **Robert (1994)** revealed a higher level of parental involvement if the programmes are family-centered. To ensure continued parental involvement, intervention programmes must focus on goals that are important to the family. Research studies indicated that parents who are committed to programme goals are more likely to carry out suggested activities, will become more skilled as teachers.

**Shuman (1996)** in her study examined the use of sensory integration techniques to reduce the maladaptive behaviours that interfered with the learning of nine high school students with mental impairments attending a special school. Maladaptive behaviours identified included rocking, toe walking, resistance to change, compulsive behaviours, aggressions, tantrums, and gagging. A literature review, examined the relationship between the senses, and behaviour of those with disabilities, the functions of nervous systems and sensory integrative processes, and various methods of behavioural intervention including aversive, drugs, megavitamins, diets, psychotherapy, auditory

integration therapy, and sensory integration techniques. The intervention involved the use of various sensory integration techniques including auditory / vestibular, visual, speech / communication, behaviour, and balance techniques. After the intervention, the teacher reported a decrease in maladaptive behaviours and increase in student enjoyment of the activities.

**Gavidia and Stoneman (1997)** determined the combined influence and predictive ability of family characteristics on maternal and paternal involvement in early intervention programmes. Mothers and fathers completed a battery of self-report questionnaires related to a variety of constructs, such as family functioning, marital adjustment, social supports, stress, coping and parental involvement. Structural equation modeling was used to test the predictive ability of family variables. Two different models were developed for mothers and fathers. Results indicated significant outcomes for both groups, largely supporting the proposed model. The coping variable emerged as a significant predictor of maternal and paternal involvement as well as mediator variable between family functioning and parental involvement.

Another study on family centered early intervention in Singapore was conducted by **Quah (1997)**. This paper described the pilot project on early intervention of 40 disabled infants between the ages of 2 and 5 years. Its main objective was to look into the feasibility of integrating children with mild disabilities into main stream preschool centres in Singapore. The intervention goals were related to the problems encountered by the children, their families and teachers. Professional staff such as occupational therapists, physiotherapists, speech therapists and psychologists intervened through providing consultations to parents and teachers who were taught the intervention follow up. An evaluation conducted after 9 months of the programme (i) showed high levels of peer and school personnel acceptance, (ii) indicated that project ASSIST was an important service to both children and their families, and (iii) demonstrated the feasibility of integrating children with disabilities into mainstream preschool centres.

**Mark et al., (1997)** conducted a four-phase study in the 4 young children who displayed aberrant behaviour. Phases 1 and 2 consisted of a series of descriptive and experimental analyses to identify the environmental antecedents and consequences that controlled aberrant behaviour. Phases 3

and 4 evaluated the short and long-term effects of treatment on aberrant behaviour, target mands and collateral (social and toy play) behaviours. The effects of treatment were monitored for up to 27 months to assess long-term suppression of aberrant behaviour. The assessment results successfully identified environment events that occasioned and maintained aberrant behaviour for all children. The short-term treatment resulted in immediate decreases in aberrant behaviour for 3 or 4 children. Long-term treatment was successful for all children and was correlated with substantial response generalization.

**Rani and Reddy (1999)** investigated a study on the involvement of parents in training children with mild mental retardation of rural areas in self care and play skills. It was found from the results that majority of the mothers were unemployed and they were the major care taker for almost all the children. The reinforcement provided by the mothers at home during the course of intervention programme helped the target group in acquiring the target skills i.e. self care and play skills. Respondents showed good improvement in self care skills than play skills as they were easy to learn and also needed for their day to day living. Thus there was an improvement in skill learning in the retarded children because of the parent participation and training. This shows that any training programme can help the retarded to function up to the level of their ability.

**Duffy and Fuller (2000)** the present study investigated the effectiveness of a music therapy programme in the enhancement of the social skills of children with moderate intellectual disability. Thirty-two children (age range = 5 – 10 years) from intellectual disability centres participate. At each centre, four children were randomly selected to participate in the music therapy programme, while four children were assigned to a non-music control group programme. One staff member was trained in each group procedure at each centre, and requested to run 30 min group sessions twice weekly over an 8 week intervention period. Five social skills were targeted for intervention: turn taking, imitation, vocalization, initiation and eye contact. Measures of effectiveness involved comparison of pre-intervention scores on five target skills using a brief social skills test specifically designed for the study. Evaluation forms completed by teachers also provided feedback on the

effectiveness of the intervention. The results reflect significant improvements in the five target social skills across both conditions following the 8-week intervention. However, this difference was found to be independent of the music / non-music intervention.

Studies conducted on the parental training programme brought to the forefront that when the mother was deeply involved in home training programme, there was tremendous improvement in the children. Only few studies delved into the early intervention services. In majority of the studies, parents were given training with regard to behaviour management of the children, and developing communication and daily living skills. Studies showed improvement in the condition of the children as well as perception of the parents. Most of the researchers carried homebound training program. All most equal number has been conducted both in India and abroad in this area.

## **2.2 IMPLICATION FOR THE PRESENT STUDY**

Attempts have been made to see the effectiveness of an intervention programme. Parental need for behavioural modification in their children with mental retardation was found in most of the foregoing studies. Very few intervention programmes have involved other family members viz., siblings and grandparents, apart from parents. Researches related to family stress were limited.

Attitude and perceptions of parents towards, their child with mental retardation is negative in few cases. A notable number of literate parents expected total cure for their children after intervention in one study. Goal directed parent-training approach brings about attitudinal change and improvement in the child's functioning in some studies. It was concluded in one study that family's strata and education of the mother were not only important factors in child rearing attitudes but other psychological variables are equally important. In a few programmes, it is revealed that where mother is involved, the programme proved beneficial. It is revealed in some studies that long-term treatment was successful for all children and was correlated with substantial response generalization. Semi structured interview approach was used mainly in studies and content analysis were used to analyze data. In some, multiple

regression analyses was employed to determine the set of independent variable that best predict each dependent variable.

In the evaluation of the intervention programmes and services in the foregoing study, many programmes have been tried out and assessed, in many cases bringing out the effectiveness of such programmes. 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.

In the light of the above observation, it can safely be said that if the needs of the family in totality are assessed, only then the programme can be useful and effective.

It is evident from the researches reviewed that more studies with regard to family involvement, impact on family, role of other family members are conducted in abroad whereas almost equal number of studies have been conducted in the areas related to parental perceptions and attitudes towards the children with mental retardation and parental training.

The present study tries to assess the needs of the parents of children with mental retardation in Baroda city and an attempt has been made to develop the intervention programme and see its effectiveness through follow up studies as follow-ups were also not taken up by the studies conducted in this area.

Questionnaires were the major tools used for the collection of data with interviews and casual observations supplemented the other relevant information that was not covered in the questionnaire. Very few dissertations at doctoral level and master's level have been conducted in this area

The foregoing discussion of the researches presented put forth some of the observation that may help in formulating the present problem. Parental training / intervention programmes in our country are in operation for quite sometime, still it has not drawn that much attention of the researchers. Limited studies have been conducted so far and no recent study has been seen in this area. An overall review of the research studies, compiled here, reflects that researches in developed countries have out numbered the studies done in developing countries. It might be due to the already existing and easy

accessibility of the professionals and the centres / institutions for these children. Developed countries are in a position to provide funds for social welfare aspects whereas developing countries have been struggling everywhere in the present competitive world. They are not in a position to spare funds for such purposes. These countries are lagging behind in this respect due to lack of awareness and inadequate knowledge. Research in this area is still in its infancy.