Chapter Two:

REVIEW OF STUDIES

Section I:
Foreign Studies

Section II:
Indian Studies
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In this chapter, studies regarding stress and coping in the families of mentally retarded individuals are reviewed in two sections: (1) Foreign studies and (2) Indian studies. There are many foreign studies and some relevant studies from the year 1997 onwards have been selected. There are few studies in India and most of the relevant studies have been reviewed. Studies are discussed under four headings namely- (1) Studies on Stress, (2) Studies on Behaviour Disorder, (3) Studies on Siblings, and (4) Studies on Coping.

(1) Studies on Stress
Studies on stress are reviewed in this section and most of the studies deal with coping aspect also.

Heller, Hsieh & Rowitz (1997) compared the objective (time demands and support provided) and subjective dimensions (care giving burden) of care giving for fathers (aged 25-82 years) and mothers (aged 25-79 years) from 113 families of children and adults with mental retardation living in the family home and in other settings. In comparison with fathers, mothers spend more time providing care, offer more types of support, and perceive more care giving burden. For both parents out-of-home placement of adults, but not children, is associated with less care-giving burden. The behaviors and health of the offspring have a greater impact on mothers than on fathers. The effects of their own time commitments
and their spouse's time commitments on their care giving experience differ for mothers and fathers.

Scott, Atkinson, Minton & Bowman (1997) compared the distress level of parents who had infants with Down’s syndrome to that of control parents of infants without disability. Analysis of pooled data indicates significantly greater depression for the study subjects, however effect sizes are small and the prevalence of clinical depression is 5.56% among matched study parents and 4.26% among unmatched study parents. It is concluded that parenting an infant with Down’s syndrome may cause less distress than previously thought.

Blacher, Shapiro, Lopez & Diaz (1997) investigated contributions to depression in 148 Latina mothers with and 101 without children (ages 3-19 years) with mental retardation. Depressive symptoms were assessed using the Center for Epidemiologic Studies -Depression scale. Depression is elevated in both Latina samples in comparison to a normative group. Latina mothers who had children with mental retardation show significantly higher levels of depressive symptoms compared to controls. Depression is predicted by low family cohesion, poor health of the mother and absence of spouse or partner, less use of passive appraisal as a coping strategy, and presence of a child with mental retardation.

Haveman, Van, Raijnders & Heller (1997) compared the service needs, time demands, and subjective burden of parent caregivers of children and adults with mental retardation across the life cycle. They also examined the extent that family and child characteristics and service use contributed to parents' time demands and burden. This population-based study in the Netherlands included 2,573 parents of children with mental retardation living at home. There are significant differences by age of the child in demographic characteristics of the family, child's level of disability and adaptive functioning, service use, care giving time demands, and subjective care giving burden. The level of education of parents, the child's level of disability, and service use are associated with parental time demands and care giving burden.
Feldman, Maurice & Walton (1997) examined stress in parents with low IQ as a potential contributor to their parenting problems. 82 mothers with intellectual disabilities (IQ < 80; labeled as having mental retardation) were given the Parenting Stress Index (R. R. Abidin, 1990). Results indicate very high levels of overall stress, stress related to child characteristics, and stress related to other life experiences as compared to the normative test group. Subjects are divided into 3 groups depending on the age of their children (infants/toddlers, preschool or school age children). The mothers with school-age children report significantly higher stress than those of infant/toddler and preschool children. Child age and living in a crowded environment were significant predictors of parenting stress.

Fullmer, Tobin & Smith (1997) explored the relationship between offspring gender and care-giving. 235 Mothers (aged 58-96 years) of adults (21-68 years) with mental retardation were interviewed. No demographic differences are found between mothers with daughters and sons. The study finds that mothers are less likely to use day-services for their daughters. Mothers with daughters are more likely to feel burdened by care giving and express a need to be constantly vigilant. However, mothers receive the maximum help from daughters with regard to household tasks.

Padeliliadu (1998) studied the relationship between the time demands and stress in 41 mothers of Down’s syndrome children and 41 mothers of non-disabled children. Results reveal increased time demands on the mothers of children with Down syndrome in terms of recreational/ educational activities and total time demands. Mothers with Down’s syndrome children perceive, time spent with their children less positively and stress is more in mothers of Down’s syndrome children than the mothers of the comparison group.

Pelchat, Richard, Bouchard, Perreault, Saucier, Berthiaune & Bisson (1999) studied 144 parents with children with different diseases. The study finds that parents of infants with Down’s syndrome and with congenital heart disease
report greater levels of parenting stress and psychological distress than parents of babies with cleft lip and/or palate or non disabled infants. Mothers report greater levels of stress and distress overall, but differences across diagnostic groups are similar for mothers and fathers.

**Benchot (1999)** studied 66 older parents and find that parents reported more hassles with their mentally retarded adult child’s behaviour and cognitive status than with the physical activities involved with care giving. This type of stress is significantly related to depressive symptoms in parents. Parents report higher stress if the child’s condition is rated to be severe. Parents use problem focused and emotion focused coping equally in managing their stress.

**Hodapp & Dykens (2000)** examined whether stress levels differ in families of young children with 3 different genetic etiologies of mental retardation, and whether child characteristics associated with those genetic etiologies may help explain these differences. Participants included 60 families of young children with Down’s syndrome, William’s syndrome, and Smith-Magenis syndrome. All children were between the ages of 3 and 10 years. Parents completed Achenbach’s Child Behavior Checklist, the Questionnaire on Resources and Stress-Friedrich edition, and a demographic questionnaire. Families of children with Down’s syndrome experience significantly less pessimism than the other two etiology groups and significantly less parent and family problems than families of children with Smith-Magenis syndrome. The strongest predictor of parent and family problems is maladaptive behavior in Smith-Magenis syndrome, younger age in Down’s syndrome, and both maladaptive behavior and younger age in Williams syndrome. Maladaptive behavior predicted pessimism in families of children with Smith-Magenis syndrome, but none of the variables examined significantly predict pessimism in the other two syndromes.

**Shearn & Todd (2000)** examined the nature of the restrictions which affect the employment participation of mothers of children with disabilities and explored the meaning work has for them. 18 mothers, aged up to 41 years, of children with
disabilities aged 5-15 years were interviewed. These mothers found employment difficult. They encountered unusual time demands, and a lack of adequate and affordable childcare. Furthermore, they felt that their employment opportunities were restricted by attitudes prevalent in society concerning appropriate roles for women, especially mothers of children with disabilities. The lack of opportunities to engage in employment led, in varying degrees, to feelings of isolation, a lack of fulfillment and low self-esteem. The mothers felt that they were on the periphery of society with little release from the pressures of caring. Mothers who had part-time jobs often did poorly paid work of low status, thereby encountering few opportunities to use their skills and abilities to the full. Those, who attempted a full-time job, experienced stress from the dual demands of home and work, and from a fear that they were failing as mothers.

Van (2000) examined the relationships among family demands, family resources and family problem solving communication, family coping and sibling wellbeing in 41 families of children with Down's syndrome. Results indicate that as a group the siblings in this study have favourable self-concepts. In addition, maternal reports typically indicate that these siblings are socially competent with a low incidence of behaviour problems.

Hedov, Anneren & Wicblad (2000) studied 165 parents of 86 Down's syndrome children and assessed 8 health domains; including physical functioning, vitality and mental health. Mothers report health problems more frequently than fathers. Mothers of Down's syndrome children report significantly lower vitality scores than did fathers. Also they report lower scores in mental health and tendencies to lower scores in another four domains compared with mothers of children without Down's syndrome children. Fathers of Down's syndrome children have lower scores for vitality and mental health compared with fathers of children without Down's syndrome.

Baxter, Cummins & Yiolitis (2000) investigated stress attributed by parents to their family member with intellectual disability over a period of seven years in
relation to specific foci of parental worry, and also in relation to stress attributed to the youngest sibling without a disability. 44 parents of 10-12 years olds, 29 parents of 17-19 years olds, and 20 of 24-26 years olds were interviewed. The stress parents attributed to their family member with a disability is about double that attributed to the youngest sibling without a disability. However, multiple regression analysis reveals that the stress attributed to the sibling without a disability actually accounted for most of the variance in explaining the stress attributed to the family member with a disability. The results suggest that the stress attributed to any specific child may be an indicator of more general family stress. It is also found that, while the strength of parental worry decreased, the pattern of worries does not change over time, nor do the specific foci of worry differentiate low-stressed from high-stressed parents.

Gosch (2001) compared the stress levels in 85 German mothers of children with mental retardation [William's syndrome (25), Down's syndrome (13), mental retardation of other etiologies (22) and in mothers of non-disabled children (25)]. The groups were matched according to the children's age, sex, and verbal comprehension. Subjects completed the Parenting Stress Index (PSI; R. R. Abidin, 1990) and the German version of the Child Behavior Checklist. Significant differences are found in the child domain of the PSI, but not in the parent domain. The degree of the children's mental retardation as well as conspicuous behavior correlated positively with maternal stress. The findings indicate that generally, mothers of children with mental retardation, regardless of its etiology, find it more difficult to accept their child than do mothers of non-disabled children.

Rimmerman & Muraver (2001) examined the extent to which 160 mothers (mean age 68.6 years) who care for an adult child with mental retardation differ in respect to undesired daily life events, instrumental functioning, social support and well-being from a comparably matched group. Participants completed questionnaires on undesired daily life events and related scales. Findings indicate that caregivers for adult children with mental retardation report more undesirable daily life events in comparison to the matched group. However, no
differences are found in respect to their instrumental functioning, social support and well-being.

**Pisula & Gorska (2002)** studied the relationship between the level of child intellectual disability and the parent’s marital quality. Three groups of parents compared: parents of mildly retarded children (13 couples and 2 single mothers), parents of moderately or severely retarded children (15 couples), and parents of normally developing children (30 couples). The scales for marital satisfaction, marital intimacy, social support, and the marital problems were administered. The results indicate that the level of intellectual disability of the child does affect the marital quality in some limited areas. The parents of moderately or severely retarded children scored lower on the marital intimacy and cooperation scales than their counterparts.

**Magana, Seltzer, Kruass, Rubert & Szapocznik (2002a)** examined predictors of depressive symptoms and care giving burden in Cuban-American and Puerto Rican caregivers of adult children with mental retardation. 44 Puerto Rican mothers (aged 55 years) and 49 Cuban-American mothers (aged 55 years) of mentally retarded adult children completed questionnaires concerning: (1) Services received by the child, such as therapy, psychological, and legal services; (2) Family problems; (3) Depressive symptoms; and (4) Caregiver burden. American subjects report higher socioeconomic status than did Puerto Rican subjects. There is a substantial amount of within-group heterogeneity in family socio demographic characteristics, linked closely with immigration patterns for Cuban-American subjects. However, subjects in families with more problems have higher levels of burden and depressive symptoms, even after accounting for socio demographic diversity and ethnicity.

**Withers & Bennett (2003)** made a case study of a female (aged 5 years) with profound physical and intellectual disabilities. It discusses the pressures involved in caring for the child, and describes an intervention. According to social services, the subject would be likely to suffer emotional distress if she spent long
periods of time away from her family and in a variety of settings. The mother had ambivalent feelings toward her and was finding it difficult to deal with her husband's negative feelings towards their daughter. At the time of the intervention, the parents had been experiencing considerable marital difficulties and were contemplating a separation. They had also encountered difficulties in coping with the practical demands of caring for their daughter and in obtaining appropriate respite services. Following the intervention, the emotional climate regarding marriage was reportedly much improved and the parents felt more able to cope with the strains of caring for their daughter.

Ricci & Hodapp (2003) examined father's perceptions of stress relating to and involvement with children with Down's syndrome (DS) (N = 30) versus those with other types of intellectual disability (ID) (N = 20). The ages of children in both groups ranged from 3 to 22 years, with average ages of 10-11 years in each group. Fathers and mothers completed questionnaires about their children's personalities and maladaptive behaviours, their own parenting stress, and the fathers' level of involvement. Both fathers and mothers rate their children with DS as having more positive personality traits and less maladaptive behaviour. Possibly because of these positive perceptions, fathers of children with DS also report less child-related stress, particularly in the areas of acceptability, adaptability and demanding nature. The two groups of fathers are very similarly involved in child rearing.

Goldman (2003) studied families with the child living at home (N = 50) and placed out (N = 50). Family adaptability and cohesion were assessed using Olson's FACES II. Family satisfaction was assessed using Olson's Family Satisfaction Scale (FSS). Behavior problems were assessed using Connor Abbreviated Symptom Questionnaire (ASQ). FACES II and the FSS were completed individually by each parent; the ASQ was completed by the primary caregiver. Data were also gathered concerning family demographics and individual child characteristics. T-test, Chi-square, Discriminant function analysis, and ANOVAs tested differences between the two placement groups (home vs.
not home) in family and adaptability and cohesion, family satisfaction, behavior problems and demographic variables. Correlations between the outcome and predictor variables were also performed. Results strongly suggest that both qualities of the individual and qualities of the family have a bearing on placement, although individual characteristics of the child appears to be much more important than the characteristics of the family.

**Duygun & Sezgin (2003)** explored three dimensions of the Maslach Burnout Inventory (MBI) in a sample of mothers; to compare the burnout levels, stress symptoms, coping styles and perceived social support of mothers with mentally handicapped and healthy children; lastly, to investigate predictive level of the stress symptoms, coping styles and perceived social support on the burnout levels of the two group of mothers. The sample consisted of 118 mothers of mentally handicapped and 121 mothers of healthy children. The results of one-way ANOVAs indicate that there are significant differences between the emotional burnout levels and submissive coping style levels of two groups of mothers; the mothers of mentally handicapped children having higher scores than the mothers of the healthy children on two factors of MBI and the submissive coping style factor of the Coping Style Scale. Hierarchical regression analysis revealed that personal accomplishment factor of MBI, cognitive-affective factor of the Stress Self-Assessment Checklist, submissive style factor of the Coping Style Scale and seeking for social support factor of the Multidimensional Scale of Perceived Social Support Scale are the best predictors of burnout in the mothers of the mentally handicapped children.

**Magana, Seltzer & Krauses (2004)** studied differences in depression between Puerto Rican and non-Latina White mothers providing care to their adult child with mental retardation. The focus of this study is on how family problems may mediate the effect of the adult's behavior problems on the mother's level of depressive symptoms and how this process differs across the two groups of mothers. As hypothesized, family problems is a stronger predictor of depressive
symptoms for Puerto Rican mothers than for non-Latina White mothers. In addition, Puerto Rican mothers are in poorer physical health, which further accounted for differences in depression between the two groups.

**Emerson, Robertson and Wood (2004)** aimed at identifying factors associated with the level of psychological distress reported by urban family carers of children with intellectual disability. Information was collected by postal questionnaire (or interview for family carers who did not have English as their first language) from the family carers of 408 children with intellectual disability (31% of all children within the area administratively identified as having an intellectual disability). Results indicate that 47% of primary carers score above the threshold for psychological distress on the General Health Questionnaire (GHQ). Scoring above the threshold is strongly related to the emotional and behavioural needs of the index child; South-Asian ethnicity; and moderately associated with the severity of the child's delay in communication.

**Essex & Hong (2005)** based on a sample of 126 families, investigated how division of household labor is related to marital satisfaction and care giving burden among older married parents, caring for adult children with intellectual disabilities. For mothers, greater spousal participation in household work and satisfaction with the division of labor are positively related to marital satisfaction. Satisfaction with division of labor also appeared to buffer maternal care giving stress, decreasing the relationship between behavior problems of the adult child and caregiver burden. For fathers, there is no relationship between division of household labor and marital satisfaction. Behavior problems of the adult child predicted paternal care giving burden only when men are satisfied with the labor division.

**Hassall, Rose & McDonald (2005)** investigated the relationships between parental cognitions, child characteristics, family support and parenting stress. The aspects of cognitions studied were: parenting self-esteem (including efficacy and satisfaction) and parental locus of control. The group studied consisted of 46
mothers of children with intellectual disability. The Vineland Adaptive Behavior Scale and Maladaptive Behavior Domain were administered by interview. Mothers also completed four questionnaires: the Family Support Scale, the Parenting Sense of Competence Scale, a shortened form of the Parental Locus of Control Scale and the Parenting Stress Index. Data were analyzed using Pearson's correlation coefficients, partial correlations and a regression analysis. The results indicate that most of the variance in parenting stress is explained by parental locus of control, parenting satisfaction and child behaviour difficulties. Strong correlation between family support and parenting stress is mediated by parental locus of control. The results demonstrate the potential importance of parental cognitions in influencing parental stress levels.

Fujuan & Li (2005) investigated the stress and relevant factors of 200 MR children's parents. No significant sex difference is found in the stress of parents of MR children. There is a significant group difference in the stress of MR children's parents. There is significant correlation between stress of MR children's parents and behaviour of MR children, coping, and quality of life.

(2) Studies on Behaviour Disorder

Hodapp, Dykens & Masino (1997) examined stress-support in 42 families of 3-18 years old children with Prader-Willi syndrome. In comparison with reported stress levels in families of children with mixed etiologies of retardation, parents of children with Prader-Willi syndrome showed higher levels of parent and family problems and comparable levels of pessimism. Parents of such children listed other family members and friends as their main supports. Although the child's age, IQ and degree of obesity are not related to family stress; families experienced greater stress when the child showed more behaviour problems.

Floyd & Gallagher (1997) analyzed data obtained from mothers and fathers of 231 children (aged 6-18 years) with mental retardation (MR) or chronic illness (CI), and a non-disabled behavior-problems sample. Mothers identified fewer
behavior problems in children with MR and more in children with CI than did teachers. The presence of significant behavior problems is more important than disability type in determining most forms of parental stress, and predicted mental health services use. MR group parents worry most about providing ongoing care into adulthood. Single mothers are not more stressed, but used more services than two-parent families.

**Baker, Blacher & Crnic (2002)** examined for early evidence of behavior problems in 225 children aged 3 years, with or without developmental delays and the relative impact of cognitive delays and problem behaviors on their parents. Staff completed Bayley Behavior Scales and parents completed Child Behavior Checklists (CBCL). Problems are found to be more in children with delays than in those without delays. Parenting stress is higher in delayed condition families. Regression analyses revealed that the extent of child behavior problems is a much stronger contributor to parenting stress than is the child's cognitive delay.

**Dekker & Koot (2003)** studied 474 mentally retarded individuals attending special schools, aged 7-20 years. Results indicated that 21.9% had anxiety disorder, 4.4% had mood disorder and 25.1% had disruptive disorder (behaviour problems). Out of these 374 children 27% received psychiatric treatment. They studied 968 parents of such children and found social incompetence, inadequate daily living skills, child health problems, negative life events, emotional and behavioural problems and parental mental health problems as the strongest predictors of problems in the child.

**Baker, McIntyrease & Blacher (2003)** studied the early manifestation and continuity of problem behaviours in pre-school children with (N=82) and without (N=123) developmental delays. Behaviour problems are quite stable over the year from age 36-48 months. Children with developmental delays are rated higher on behaviour problems than their non-delayed peers, and are three times as likely to score in the clinical range. Mothers and fathers show high agreement in their rating of behaviour problems, especially in the delayed group. Parenting
stressed is also higher in the delayed group, but is related to the extent of
behaviour problems rather than to the child's developmental delay. High
parenting stress contributed to a worsening in child behaviour problems over
time, and high child behaviour problems contributed to a worsening in parenting
stress. Findings for mothers and fathers are quite similar.

Beck, Hastings & Daley (2004) studied 74 mothers of children with intellectual
disabilities. The mothers completed measures of stress and mental health and
reported on their child's adaptive behaviour, problem behaviour, and pro-social
behaviour. Regression analyses revealed that the child's behaviour problem is an
independent positive predictor of maternal stress; the child's pro-social behaviour
is a negative predictor of maternal stress; and adaptive behaviour is not a
predictor. These results support the need for more research on the pro-social
behaviours of children with intellectual disabilities, especially their putative impact
on parental well-being.

Blacher & McIntyrease (2006) examined whether behaviour problems and
adaptive behaviour of low functioning young adults, and well-being of their
families, varied by diagnostic syndrome [intellectual disability (ID) only, cerebral
palsy, Down syndrome, autism], as well as by cultural group. Behaviour disorders
in young adults with moderate to severe ID were assessed from information
provided by 282 caregivers during in-home interviews. The sample consisted of
150 Anglo participants, and 132 Latina, primarily Spanish-speaking, participants
drawn from Southern California. Behaviour disorders and maternal well-being
shows the same pattern across disability syndromes. Autism is associated with
the highest scores in multiple behaviour problem areas as well as maternal
reports of lower well-being. Down's syndrome is associated with the lowest
behaviour problem scores and the highest maternal well-being. When behaviour
problems are controlled for, diagnostic groups accounted for no additional
variance in maternal stress or depression. The pattern of behaviour problems
and well-being does not differ by sample (Anglo vs. Latina), although level on
well-being measures does. Latina mothers report significantly higher depression
symptoms and lower morale, but also higher positive impact from their child than does Anglo mothers. Caregivers of young adults with autism report more maladaptive behaviour problems and lower personal well-being; and stress; relative to other diagnostic groups, regardless of cultural group. However, cultural differences exist in caregiver reports of depression, morale, and positive perceptions.

Hastings, Daley & Burns (2006) assessed mothers of children with intellectual disability at two time points, 2 years apart (N = 75 at Time 1, N = 56 at Time 2). Data were gathered on maternal distress, mental health, expressed emotion, and the child’s internalizing and externalizing behavior problems. The study finds that maternal distress and children’s behavior problems entered into a bidirectional relationship over time. This relationship is found to be specific to externalizing problems. Exploratory analyses also suggest that maternal distress and depression have a bidirectional longitudinal relationship. In terms of maternal expressed emotion, criticism and emotional over-involvement is cross-sectionally but not longitudinally related to children’s externalizing behavior problems and to maternal distress.

(3) Studies on Siblings

Andersson (1997) tested 32 children (aged 6-11 years) with the Family Relations Test (FRT) and Kveback Family Sculpture Technique; half of the subjects had a sibling with mental retardation (MR) at home and the other half (matched controls) had no disabled persons in their family. Results show few differences between the groups. According to the FRT, however, the emotional involvement in the eldest non-retarded sibling differed significantly from that of the corresponding child in the control group, especially with respect to negative incoming feelings. Young siblings also tended to unconsciously place the child with MR at larger distances from themselves than they placed the other siblings. Siblings of children with MR seem to adapt to changes in the family because of
the child with MR and to qualitatively alter their thinking in relation to family members.

**Seltzer, Greenberg, Krauss, Gordon & Judge (1997b)** studied 329 siblings of adults with mental retardation contrasting them with 61 siblings (all aged 21-63 years) of adults with serious mental illness with respect to (1) the pervasiveness of the impact of the brother or sister on the sibling's life, (2) the closeness of their current relationship and frequency of contact with the brother or sister with the disability, and (3) the factors related to the sibling's level of psychological well-being. Siblings of adults with mental retardation are significantly more likely than siblings of adults with mental illness to perceive that the brother or sister had a pervasive influence on their life decisions and to evaluate their sibling experience as mostly positive. In addition, siblings of adults with mental retardation have a closer relationship with the brother or sister with the disability than siblings of adults with serious mental illness. Siblings of adults with mental retardation have better psychological well-being when they have a close relationship with the brother or sister. In contrast, siblings of adults with serious mental illness have more favorable psychological well-being when they perceive a less pervasive impact of the brother or sister on their life.

**Cuskelley, Chant & Hays (1998)** studied 45 families with a child with Down's syndrome and 88 comparison families. No differences are found between the siblings of a child with Down's syndrome and comparison children on mother or father's reports of problem behaviour. Siblings of a child with Down's syndrome also does not differ in their contribution to family tasks, however, for the brothers of a child with Down's syndrome there are significant negative correlations between household tasks and behaviour problems on father's report. Parents of a child with Down's syndrome report more stress than comparison parents and stress is related to reports of problem behaviour for some parent groups.

**Eisenberg, Baker & Blacher (1998)** studied 25 adolescent siblings of children with mental retardation living at home and 20 adolescent siblings in residential
placement, contrasted with 28 siblings of children without retardation, on measures obtained from their mothers and themselves. Subjects were interviewed using measures that assessed psychological adjustment, perceptions of the family environment, relationship with the target child, perceived impact of the target child on the sibling, thoughts about out-of-home placement; their mothers were interviewed concerning family demographics, target child functioning, and their perception of the sibling's adjustment and family stress. Results show that the subjects are highly similar on measures of psychological adjustment, self-esteem, and family environment. Sibling relationships, however, are less intense with less warmth but also lower conflict, in families where the child lived out of the home. It is concluded that most siblings of children with retardation report positive personal growth experiences while also expressing realistic concerns about the future.

Greenberg, Seltzer, Orsmond & Krauss (1999) examined the factors associated with the involvement of siblings (mean age 41-42 years) in the life of a brother or sister who has mental illness or mental retardation. Involvement was defined as the current provision of instrumental and emotional support as well as the expectation of future care giving responsibility. A mailed questionnaire was used to collect data from 61 siblings of adults with serious mental illness (mean age 39 years) and 119 siblings of adults with mental retardation (mean age 40 years). The sample was drawn from two ongoing longitudinal studies. The two groups of siblings show striking differences in their expectations about their responsibility for future care giving. Almost 60% of the siblings of adults with mental retardation expected to assume primary care giving responsibility in the future, but only one-third of the siblings of adults with mental illness held this expectation. For both groups, competing family responsibilities limited the involvement of siblings, whereas closeness to the family of origin led to greater sibling involvement. The extent of current and future involvement by siblings of adults with disabilities is a function of the demands and constraints of midlife as well as the degree of closeness with the family of origin.
Fisman, Wolf, Ellison & Freeman (2000) examined the unaffected siblings of two different groups with chronic disabilities, pervasive developmental disorder and Down’s syndrome over 3 years comparing their adjustment with each other and with the siblings of a non-disabled group. This study examined 137 siblings initially and 127 at follow-up 3 years later. Significantly more adjustment problems are found in the siblings of the pervasive developmental disorder children at both times when compared with siblings of Down’s syndrome and control children. Caregivers of pervasive developmental disorder children report the highest levels of distress and depression and this persisted over time. Parent’s distress is found at both times to be related to sibling adjustment problems regardless of study groups.

Orsmond & Seltzer (2000) studied differences and similarities between 78 brothers and 167 sisters (aged 21 -59 years) of adults with mental retardation with respect to the instrumental (care giving, companionship) and affective (positive affect, emotion) aspects of the sibling relationship. Sisters scored higher than brothers in the care giving, companionship, and positive affect aspects of the sibling relationship. Brothers’ sibling relationships are conditioned by the gender of the sibling with mental retardation. Brothers of brothers with mental retardation have a more favorable emotional response than does brothers of sisters.

Egan & Walsh (2001) noted that siblings play an important role in the lives of their brothers and sisters with intellectual disability when they reside in the parental home. Many assume a primary care giving role following the death of their parents or when parents are no longer able to give care. Sources of stress reported by 39 adult siblings of Irish men and women with intellectual disability were explored. Siblings who are primary caregivers are older and earned less income than their counterparts in a second group who lived in the parental home and who have an especially close bond with their brother or sister with intellectual disability. Perceived social support as well as their brother or sister’s independence is significantly related to the stress reported by siblings on the
short form of the Questionnaire on Resources and Stress. Neither levels of reported stress nor the presence of a plan for their relative's future distinguished the two groups of siblings.

Fahey (2005) attempted to determine whether siblings of individuals with mental retardation are in fact at higher risk for maladjustment than a control group of individuals whose siblings do not have disabilities. 58 adult siblings of individuals with mental retardation completed a packet of questionnaires including the Beck Depression Inventory - Second Edition (BDI-II; Beck, Steer and Brown, 1996), the Beck Anxiety Inventory (BAI; Beck, 1990, 1993), the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1993), and the Questionnaire of Resources and Stress-Friedrich (QRS-F, Friedrich, 1983) via mail. A control group of 58 adults of individuals who did not have a sibling with mental retardation participants completed the packet of questionnaires, with the exception of the Questionnaire of Resources and Stress as it did not apply to them. Analyses indicated the opposite of the hypothesis. Siblings of individuals without mental retardation have significantly higher anxiety and depression scores on the BAI and the BDI-II than siblings of individuals with mental retardation. Overall, the siblings of adults with mental retardation in this study are a resilient group with positive coping skills. A relationship between high levels of stress as measured by the QRS-F and emotion oriented coping is found. Emotion oriented coping is related to anxiety and depression. Perhaps learning to meet the demands of a sibling with mental retardation fosters a sense of competence and maturity that leads to positive coping skills and positive psychological outcomes.

(4) Studies on Coping

Greenberg, Seltzer, Krauss & Kim (1997) contrasted 73 aging mothers (aged 55 years and older) of adults with mental illness and 288 aging mothers of adults with mental retardation with respect to their levels of stress, social support
resources and the extent to which social support was predictive of their level of care giving burden and depressive symptoms. Although mothers of adults with mental illness have smaller social support networks than mothers of adults with mental retardation, they are more likely to be members of support groups and have at least one friend also caring for a relative with disabilities. In addition, social support is a more prominent predictor of changes in burden and depressive symptoms in mothers of adults with mental illness, suggesting the importance of the social context for their psychological well-being.

Hyden & Heller (1997) examined the relations between service and support utilization, problem-solving/coping strategies, and level of personal burden experienced by 44 younger (aged 32-55 years) and 61 older (aged 56-86 years) immediate and extended family caregivers of adults with mental retardation. There are no differences in the number of support services received. However, younger caregivers report significantly more unmet service needs and rated significantly more of them as a critical or an emergency need. Both groups have developed effective problem-solving skills. However, older caregivers are more likely to seek spiritual support and the younger caregivers more apt to mobilize their families to acquire and accept help. Older caregivers experience significantly less personal burden. Younger caregivers are more predisposed toward seeking outside help and have higher expectations of the service system.

Costigan, Floyd, Harter & McClintock (1997) examined the family problem-solving interactions in 165 families of school-aged children with mild or moderate mental retardation and a comparison sample of 52 families. Results demonstrate a disruptive impact of children with mental retardation in the form of more directive-ness by mothers and fathers, less supportive problem solving by single mothers and less active problem solving by the target children in the mental retardation group. The absence of high rates of aversive behaviours in the mental retardation group and the similarities in sibling's behaviours across the groups suggest that the mental retardation families are also resilient in the face of special demands. Role differences among mothers, fathers and siblings also
are highly consistent in the two groups. Evidence of difficulties for single mothers and problem behaviours by other children in the family suggested that mental retardation is one of the many challenges that families learn to cope successfully.

Guess (1998) investigated parental coping strategies and perceived parenting stress within groups of parents of preschool children with disabilities and preschool children without disabilities. Parents of preschoolers with mental retardation, autism, and with no disability were compared on a measure of perceived stress associated with the parent-child relationship and a measure of coping. Chi-square analyses indicate that significant differences do not exist between groups of parents on scales associated with depression, stress related to parent characteristics, or total stress. Analyses of variance support the hypothesis that stress is a function of coping efforts (p < 0.001) rather than of child condition.

Kim (1999) reported findings from two parallel longitudinal studies – one study on 74 aging mothers of adults with mental illness and the other study on 246 aging mothers of adults with mental retardation. Mothers caring for an adult with mental illness are daily confronted with more behaviour problems, experience a greater pile-up of other life stressors and are more likely to use emotion focused coping strategies which lead to increased levels of distress. Mothers of adults with mental retardation who made greater use of problem focused coping over time have significantly lower levels of burden and depression and better relationships with their adult child. However mothers in both groups report less distress when they use cognitive coping strategies to reframe the stressful situation.

Grant & Whittell (2000) designed a study to explore which problem-solving, cognitive, and stress-reduction coping strategies family members from 27 families found useful. 26 women and 15 men from these families were interviewed about their coping strategies. They used a coping inventory and Carers Assessment of Managing Index. Coping is shown to be differentiated
according to gender, life stage and family structure. Family carers generally use a variety of problem-solving, cognitive, and stress reduction approaches to caregiving. However, women identify a slightly higher proportion of useful coping strategies than men. Many couples adopt a sharing-caring together approach, which highlight the importance of fathers and other males in caring roles. Lone carers place a strong emphasis on cognitive coping. In terms of life stage, parents with pre-school children are less confident about their experience and expertise. Carers of school-age and younger adults share similar coping strategies. By contrast, older carers are more resigned to their role.

Simmerman, Blacher & Baker (2001) assessed the extent of father involvement in the lives of their young children (aged 8.4-14.6 years) with severe intellectual disability, as well as their satisfaction with that involvement. This study assessed 60 families (fathers aged 27-62 years, mothers aged 27-59 years) at two time points about 1.5 years apart. There is high agreement between mothers and fathers concerning the extent of fathers' help, which is highest in the areas of playing, nurturing, discipline, and deciding on services. Most mothers are satisfied with the extent of fathers' help. Mother's satisfaction with father's help relate more strongly to indicators of family well-being than the actual extent of father's help. In regression analyses, mother's satisfaction with father's help explains significant variance in mothers' and fathers' marital adjustment at both time points, even after the contributions of child maladaptive behavior and caretaking burden are accounted for.

Kroese, Hussain, Clifford & Ahmed (2002) in their study used a semi-structured interview, mothers were asked about who helped them in their parenting role and how recent and how helpful this support had been. Adapted psychological questionnaires were presented which measured affect, assertiveness and self-esteem. Mothers were also asked about the benefits, burdens and future expectations of parenthood. Data analysis included quantitative and qualitative methods. Significant associations are found between the number of reported social contacts and positive affect, the recentness of
reported social contacts and self-esteem, and the lack of self-esteem and reported burdens of parenting. The average number of social contacts reported is 6.8 persons, with only half of these being described as very helpful.

**Heller, Miller & Factor (2002)** studied how the support provided to caregivers by their adult children with mental retardation would influence care-giving appraisals and examined how severity of disability of the adult child, personal and social resources of the caregiver, and amount of caregiver assistance to the adult with mental retardation influenced care giving appraisals. Using surveys and interviews, information was collected from 80 primary caregivers (mean age 68.2 years) of adult children with mental retardation (aged 30+ years) on care-giving burden and satisfaction and six predictors of burden and satisfaction. Findings indicate that greater support from the adult child to the caregiver result in greater satisfaction and less burden.

**Bakhsh & Dirasat (2002)** examined family stress faced by mothers of mentally retarded children in relation to family needs and social support. The authors administered scales for stress, a scale for needs of parents of mentally retarded children, and a scale for social support. 100 mothers of mentally retarded children aged 24-45 years were studied. Results indicate that family stress, needs, and origins of social support follow a certain order according to their relative importance in mothers of mentally retarded children. Correlation coefficient is significant for the relation between family stress and needs, family stress and social support, and between family needs and social support. Partial r is significant between family stress and needs; and between family needs and social support; whereas it is insignificant for relationship between family stress and social support.

**Feldman, Varghese & Ramsay (2002)** examined the relationships between parenting stress, social support and mother-child interactions in 30 mothers with intellectual disabilities. All participants completed the Parenting Stress Index (PSI), the Telleen Parent Social Support Index and the Interpersonal Support
Evaluation List (ISEL). Also, 18 mothers and their children (less than 6 years of age) were observed in a 10-minutes play session at home. The mean PSI total and Child Domain stress scores are at the 85th percentile, indicating clinically significant stress. The Telleen support satisfaction (but not support size) and ISEL total scores are significantly (negatively) correlated. Support need is significantly (positively) correlated with the PSI total score. Social support satisfaction ratings are significantly (positively) correlated with positive maternal interactions. This study shows that the mothers with intellectual disabilities experience high levels of stress. And the mothers are socially isolated and report a great need for support.

Heiman (2002) examined the perspectives of parents of children with an intellectual, physical, or learning disability. 32 parents (aged 31-57 years) were interviewed as to past, present, and the modes of coping. The questions examined various aspects of family ecology domains: parent’s responses to the child’s diagnosis; patterns of adjustment; family support and services used by parents; and parent’s feelings and future expectations. Although, it is found that most parents had to make changes in their social life and expressed high levels of frustration and dissatisfaction, many try to maintain their routine life. The majority express the need for a strong belief in the child and in the child's future, an optimistic outlook, and a realistic view and acceptance of the disability. The study highlights the importance of social resources and support, and the need for effective programs of intervention.

Essex (2002) on the basis of a sample of 96 married mothers and fathers (aged 61-81 years), investigated older parents' feelings of closeness with a co-resident son or daughter with mental retardation. Mothers felt closer to the adult child (aged 21-55 years) than fathers did. For mothers, feelings of closeness to the adult child were related to their level of education and the adult child's functional skills. For fathers, feelings of closeness were associated with their own
personality characteristics, marital satisfaction, and the problem behaviors and functional skills of the adult child.

Booth & Booth (2002) analyzed the data from their three earlier studies. The data challenges the widespread assumption that men are either exploitative or bring troubles of their own to relationships. The findings show that this view presents only a part of the picture and that supportive men were in the majority among the families surveyed. Men's contributions mostly came in the form of increments to their family's human capital along with the traditional breadwinner role.

Hastings, Allen, McDermott & Still (2002a) explored the factors related to the mother's positive perceptions of their child with intellectual disability. The mothers of 41 children with intellectual disabilities completed a self-report questionnaire that measured demographic factors, child demographic variables (including caregiving demand), social support, coping strategies and dimensions of positive perceptions. Mothers' perceptions of the child as a source of happiness/fulfillment and as a source of strength and family closeness are positively associated with reframing coping strategies. Mothers' perceptions of the child as a source of personal growth and maturity are also positively associated with reframing coping strategies, the helpfulness and usefulness of support from family and friends, and the care-giving demand.

Duvdevany & Abboud (2003) examined the influence of a social support system on the level of stress and the sense of personal well-being of 100 Israeli Arab mothers of young children with special needs. 50 mothers were served by the welfare services in the Nazareth area while 50 did not get help on a regular basis. A comparison was done between educated, urban mothers, and less-educated, rural mothers. The research results point to a relationship between informal support resources, and the marital and economic stress of the mothers: the higher the amount of the informal support resources, the lower the level of stress that is experienced by the mothers. A relationship between the amount of
informal support and level of parental stress is not confirmed. A relationship between the amount of support resources and the personal well-being of the mothers is found: the higher the amount of informal support resources, the higher the sense of well-being of the mothers. A relationship between formal support, and level of stress or personal well-being is not found. Educated mothers from urban areas use the formal support less than less-educated mothers who live in rural areas.

Kim, Greenberg, Seltzer & Krauss (2003) investigated changes over time in how mothers cope with the challenges of caring for an adult child with disabilities and the effects of changes in coping on maternal well-being. A sample of 246 ageing mothers of adults with ID and 74 mothers of adults with mental illness was drawn from two parallel longitudinal studies of later-life care-giving. There is considerable variability at the individual level in the degree to which mothers change over time in their use of problem-focused and emotion-focused coping strategies. For both groups, an increase in their use of emotion-focused coping led to declining levels of well-being. For the parents of adults with ID, an increase in their use of problem-focused coping resulted in a reduction in distress and an improvement in the quality of the relationship with their adult child. For the parents of adults with mental illness, an increase in the use of problem-focused coping has no effect on levels of distress, but leads to an improved relationship with their adult child.

Blair (2003) investigated the extent of use of religious coping, in mothers and fathers who have a child with a developmental disability. The study further investigated the impact of religious coping on the perceptions these parents have pertaining to their relationship satisfaction, family cohesion, and family adaptability. In order to explore these areas, three specific questions were asked: (1) To what extent, if any, do parents who have a child with a developmental disability utilize aspects of religious coping; (2) Is there a difference between male and female caretakers of children with developmental disabilities in the extent to which they utilize religion as a coping variable; and (3) To what extent, if
any, does religious coping predict relationship satisfaction, family cohesion, and family adaptability (flexibility) in families who have a child with a developmental disability. This investigation consisted of 124 parents (62 pairs of mothers and fathers) who had a child with a developmental disability. The types of disabilities were wide ranging, with the most prevalent being Cerebral Palsy (27%), Autism (26%), Mental Retardation (13%) and Down syndrome (13%). It is found that religion as a source of providing meaning and social support is an important aspect in the lives of these parents and it is frequently utilized as a coping mechanism. The mothers in this study utilized different forms of religious coping, both positive and negative, statistically more frequently than the fathers.
(1) *Studies on stress*

Indian studies on stress are reviewed in this section and most of the studies deal with coping aspect also.

**Jain (1967)** examined the social problems related to the presence of a mentally retarded child in the family using a sample of 28 retarded and 28 normal children. Parents show marked anxiety about the future of their children; constant psychological stress; negative effect on other siblings; misunderstandings within the family; decreased interaction with neighbours and relatives; and economic loss.

**Jain & Sathyavathi (1969)** explored the problems of family with a mentally retarded child. Results indicate that 89% of the parents report their inability to carry on the routine household work satisfactorily as most of their time is spent in attending to the mentally retarded child, 82% report that their interpersonal relationships are affected, 68% found it difficult to visit their friends and relatives and 18% experience social isolation on account of the mentally retarded child.

**Narayan (1979)** studied the impact of mentally retarded children on their families. The study explored the nature and type of problems experienced by the parents and siblings of mentally retarded children in their day-to-day living. 44 cases (38 boys and 6 girls) aged 6 – 10 years with IQ below 67 were studied. A comparable 44 normal children were also studied. The tools used were an interview schedule based on that of Tizard and Grad (1961) and a modified form of Leeds Anxiety and Depression Scales. Results show that mental retardates coming from rural
and non-nuclear families pose much less problems to their mothers, the presence of a retarded child often but not always hinders the social and routine activities of the family and the retarded child invariably shows severe health problems as well as temperamental problems.

**Seth (1979)** conducted a comparative study of maternal attitudes of retarded and normal children (30 mothers in each group). Results indicate that 87% of children had to be assisted in domestic behaviours and mothers report inability to carry out household work due to caretaking burden. 83% report their social life is hampered due to loss of prestige, feeling of shame, social stigma and difficulty in visiting others and entertaining guests, 80% of mothers had guilt feelings, 73% had interpersonal problems and marital disharmony, 67% report negative effects on siblings, 63% had problems of disciplining their child, and 47% report financial burden.

**Sheshadri, Verma, Verma & Pershad (1983)** studied the impact of mentally handicapped child on 30 mothers regarding attitude, burden and marital adjustment. Parental Attitude Scale (Bhatti and Narayanan 1980), Social Burden Scale (Pai and Kapur 1981) and Marital Adjustment Questionnaire (Bhat and Gauda 1978) were used. Correlation is 0.29 between education and attitude (significant at 0.05 level) and 0.59 between IQ and social burden (significant at 0.01 level). Other correlations are not significant. Findings suggest that there is no significant marital disharmony, the burden felt by mothers is moderate to severe level; higher the level of education the more favourable is the attitude towards the retarded child; greater the degree of retardation more is the felt burden; and degree of retardation is not related to marital adjustment.

**Gandotra (1985)** studied a purposive sample of 25 families, 5 in each of the groups, orthopaedically handicapped, blind, deaf-mute, mentally retarded and cerebral palsy groups. Tools used were an Extent of Disability Scoring Sheet, Problems and Practices Rating Scale, an attitude scale and an interview
schedule. Descriptive statistics has been used for analysis of data. Results show that extent of handicap affects the problems faced by the family; caring burden, anxiety about their future employment and marriage are the primary concerns; lack of understanding about care, nature and course of disability made them experience embarrassment at having a disabled member in the family; dependence of the handicapped increases the social constraints and decreased social contacts; financial problems are experienced by all, but more so by the low income group; problems are more with the young, single and the low-income families; and positive attitude significantly reduces the extent of problems.

Moudgil, Kumar & Sharma (1985) studied 18 pairs (N=36) of parents of mentally retarded children using semi structured interview schedule to tap the daily stresses and problems of parents and a measure of emotional support. The number of fathers (first figure in the brackets) and mothers (second figure in the brackets) reporting various problems is listed here. Emotional shock (12, 16), Depression (8, 14), Arousal of guilt feelings (7, 17), Education and training problems (16, 18), Institutionalization problems (18, 18), Adjustment problems with siblings (12, 18), Social stigma (9, 14), Extra financial burden (10, 12), Chronic worries to parents (8, 17), Frequent sickness of the retarded (16, 18), Strain on marital harmony (10, 14), Strain on relations with family members (9, 17), Neglect of normal children (13, 16), Demand for extra attention (12, 17), Affected interpersonal relations in community (8, 11), Sacrificing of personal life goals (12, 16), Curtailed social engagements (14, 16), Less visits to relatives (15, 18), No education to parents of mentally retarded children (18, 18) Helplessness (18, 18). The various coping mechanisms used by parents are indifferent attitude towards the mentally retarded (10, 5), consultations with doctors (18, 18), consultations with ‘Vaids’ / ‘Hakims’ (9, 13) and approaching ‘Pandits’/ Astrologers/ ‘Sadhus’ (12, 16). Degree of social-emotional support from spouse, parents, siblings, relatives, children and friends has been analyzed. It is found that those parents who get maximum social and emotional support from spouse and family members, parents, relatives and friends experience less stress and
problems. Parents are not able to achieve some of their life goals and when the child is female it creates more social and emotional problems.

Sethi & Sitholey (1986) studied 50 mothers of mentally retarded children (up to 15 years of age), using a checklist developed by them. They report burden in the form of interference in their family routine or leisure and recreation, which even result in social, marital, familial and emotional problems in the home settings of individuals with mental handicap. Mothers in lower social class feel significantly guiltier of giving birth to the retarded child than do mothers in middle class. Mothers of middle class are less guilty because 17 out of 23 mothers are able to send their child to a special school and there they come to know that they are not the only mothers who have a retarded child. In the lower economic group 3 out of 13 mothers are able to send their children to special school. This finding is supported by the fact that mothers of special school going children do not feel that their child is a stigma on the family, whereas 50 % mothers of non-school going children feel that it is so. 90 % expected investigations and treatment, special school, occupational training and sheltered workshops for their retarded children.

Prabhu (1989) found that the presence of child with MR is a major strain on the family, especially on the mother. Constant and usual care-giving responsibilities made maximum demands on the mother's time and energies. In addition, it grossly restricts the social life of both of the parents. Most families report a fairly severe financial burden. Surprisingly, it is seen that the burden of MR is felt more by families of children with mild MR rather than those with moderate or severe retardation. 66% of the sample of mothers spontaneously report clusters of depressive symptoms.

Thressiakutty & Narayan (1990) conducted a study on parental perceptions of problems and expectations regarding their mentally retarded children. They studied parents of 100 adolescent and adult mentally retarded persons. Case history sheets were the basis for the data. Inappropriate social behaviours rank
highest (86) with regard to complaints followed by poor abilities (48), which is the next important complaint. Expectations were relatively less compared to complaints and most parents expect vocational training (49). Most of the parents complain social incompetence as hindering successful vocational training and job placement. The investigators feel that it is necessary that the parents are informed clearly about their child's level of functioning and capabilities so that their expectations can be realistic.

Sequeira, Rao, Subbakrishna & Prabhu (1990) assessed the perceived burden of mothers of mentally retarded children in relation to the degree of retardation and to the sex of their handicapped child. The second objective of the study was to know the coping styles used by the mothers. The sample was purposive and consisted of 55 mothers of 30 male and 25 female in the age range of 5-12 years with moderate (30) and severe (25) degree of retardation by using Pai and Kapur's Schedule to assess the perceived burden and a coping checklist based on Moos. Two-way analysis of variance is used to determine whether the burden experienced by mothers of mentally retarded individuals is significantly different in any of the 4 areas studied (financial, disruption of routine family activities, disruption of family interactions and family health) in relation to sex of the child and degree of retardation. A significant difference (P < 0.05: F value 6.11) in burden is observed in the area of disruption of routine family activities in terms of degree of retardation. There is no significant difference in the perceived burden with reference to the sex of the child. 66% of the mothers had a score above the mean with regard to the all pervasive burden. 70.9% of the mothers had severe strain on psychological health. More than 50% of mothers report severe financial burden. 42% report disruption in the family interactions. 52.7% felt that they are getting isolated from the social life. Coping styles are analyzed using Chi-square test. The commonly utilized coping styles by the mothers of the handicapped children are denial (used by 98.18% of the mothers), rehearsal of outcome (by 96.36%), finding a purpose (used by 85.45%), seeking emotional support (used by 83.64%) and seeking information (used by 50.91%).
Tangri & Verma (1992) studied the social burden felt by mothers of the handicapped children using Social burden Scale (Pai and Kapur 1981). The sample consisted of mothers of 50 physically handicapped and 50 mentally handicapped children in the age range of 8-15 years. The IQs of mentally handicapped children was in the range of 35-70. The physically handicapped children suffered from orthopedic handicap and had normal intelligence. The mothers of the mentally handicapped children report higher social burden than those of the physically handicapped children. It is found that the mothers of mentally retarded female children report disruption in family leisure and effect on mental health of the mothers more often.

Gaekwad (1993) made a comparison between 26 mothers of mentally retarded and 26 mothers of non-handicapped children using Hamilton Rating Scales and modified version of perceived burden. Mothers of children with mental retardation show higher depression (mean=9.50, SD=6.46) than mothers of non-retarded children (mean=6.08, SD=6.47). In mothers of younger age depression is higher (r=-0.39 and -0.24). Depression is not related to gender of the child. Stress is more in mothers of older children and not related to the severity of retardation. Relationship between stress and depression is at higher level (r= 0.67, P < 0.01). 57.6% of mothers are satisfied with social support.

Venkatesan & Das (1994) explored the nature and type of burden on family members in receiving or implementing home based training program for their children with mental handicap. They studied families of 70 retarded individuals, 44 males and 26 females in the age range of 3 months to 20 years. A semi-structured interview schedule exclusively prepared for eliciting the burden has been used. Raw data in the form of verbalizations are classified into various categories of burden (difficulties in transportation, behaviour problems in the child, demand of daily living, economic burden, physical burden, language of service provider, fits or medical problems, others and no problem). Descriptive statistics and Chi- square have been used for analysis of data. They find that presence of mentally handicapped child could become the source of burden for
the family, even though it does not appear to be significantly influenced by specific variables like child, family and service characteristics. The nature or type of burden perceived by the family members are difficulties in transportation of child (N=27), management of behaviour problems (n=26), disruption of their daily routine (N=25), economic (N=15), physical (N=10), medical (N=4) and social burden (N=4). A small percentage (N=9 or 12.86%) of parents report no burden. This study does not reveal any marked differences in perceived burden in relation to specific family characteristics, such as, family size, type or socio economic status (P> 0.05).

Annapurna (1995) studied parents of 60 mentally retarded children using Family Burden Scale (Pai and Kapur 1981), Family Satisfaction Scale (Smilkstein 1978), Socio-Economic Status Scale (Trivedi and Uday Pareek 1964) and Problem Behaviour Checklist (Peshawaria, Venkatesan & Menon 1990) and also the study used self developed tools namely Family Resources Scale, Family Coping Scale, Family Integration Scale and Family Functioning Scale. The study finds that socio economic status influences the impact of mentally handicapped children on the family. The three groups, namely - fathers, mothers and significant others do not differ in their perceptions about burden of raising a mentally handicapped child except in one dimension i.e. disruption in routine family activities.

Anand (1996) studied 60 caregivers, 30 of 4-10 years old children and 30 of 14-20 years old children using Family Assessment Schedule (Girimaji 1991) and the Coping Inventory (Billings and Moos 1984). Results indicate that daily care stress is more in parents of child than in adult mental retarded individuals, behaviour disorder in the child increases stress, 66% in each group have no marital problems, severe social stress is reported by 30% of the caregivers of the children and 27% of the young adults, 27% of caregivers of young adults and 17% of caregivers of children do not report any financial burden. However, the differences are not statistically significant except for the daily care stress.
Caregivers of young adults have higher coping scores compared to caregivers of children, the mean of appraisal coping being statistically significant. Thus, results indicate more stress in the caregivers of younger children. Even though coping is adequate in all, it is better in the caregivers of young adult group.

Ratnasbhapathy (1996) studied 37 parents with male MR children and 23 parents with female MR children (total 60) using the Questionnaire on Resources and Stress (Friedrich 1983) and short form of Coping Scale (Folkman and Lazarus 1984). The parents of severe retardation group scored highest mean score for ‘pessimism’ (mean 9.05, F=3.07, p > 0.05, NS), for ‘child characteristics’ (mean=13.70, F=24.10, significant at p < 0.001) and for ‘physical-incapacitation’ (mean=3.40, F=13.31, significant at p < 0.001 level). Thus, the pessimistic attitude increases their stress; and stress had relationship to characteristics of the child, level of retardation; and child’s physical-incapacitation. Mean coping score is high for the moderate retardation group (mean=90.4, F=2.8365, p > 0.05, NS) and least for parents of severely retarded children (mean=82.2). Better coping can be noticed in parents who have better social network system; more resources; good neighbourhood; more information available about the children’s care; intact family system; and financial support.

Chandorkar & Chakraborty (2000) studied parents of 20 mentally retarded children who were institutionalized, parents of 10 children who were not institutionalized and parents of 20 normal children. General Health Questionnaire was administered for all these 3 groups. They find that the parents of mentally retarded children have a higher prevalence of psychological morbidity than parents of normal children. Most common psychiatric disorder is depression (65%) followed by generalized anxiety disorder (30%).

Datta, Russell, Swamidas, Gopalakrishna & Seetha (2002) examined whether there is a pattern of demographic, caregiver and child characteristics that specifically predict burden among the primary caregivers of children with intellectual disability in a developing country, India. 31 consecutive families with
an intellectually disabled child were included. Caregivers and children were measured with a variety of instruments. Expressed emotion towards the child with intellectual disability predicts a high level of burden among the caregivers. Age of the child and income are also clinically associated with burden.

Gupta & Jain (2002) studied 30 parents of children with spastic cerebral palsy by using “Parents Problem Questionnaire” developed by the investigators. More educated (N=17) and less educated (N=13) differ significantly at 0.01 level (t value =5.19). High income group (N=24) and low income group (N=6) differ significantly at 0.05 level (t value =2.49). Service class (N=21) and business class (N=9) do not differ significantly. Urban (N=24) and rural (N=6) differ significantly at 0.01 level (t value=3.78). Less educated, low income group and rural parents have more problems about their spastic mentally handicapped children.

Venkatesan (2003) studied a selected group of 57 families out of the sample undergoing home training and another group of 32 families not undergoing home training program using Demographic Data Sheet, Family Barriers Identification Scale, Family impact & Burden Scale, Family Knowledge & Opinion Questionnaire, Family Involvement Schedule, Pro-forma for recording home based training schedules in individual cases, Activity Checklist for Preschool Children with Developmental Disabilities and Behaviour Assessment Scales for Indian Children with Mental Retardation: Part B. The study reports that out of 109 cases 24 (22.02 %) have behaviour problems. The most commonly reported problems are violent and destructive behaviour (in 20 out of 24), temper tantrums (19 out of 24) and self injurious behaviour (10 out of 24). Parents resort to reward-oriented techniques (57.89 %) more often than the punishment-oriented techniques (32.33 %) for management of these behaviour problems. It is noted that boys are rewarded (63.01 %) more often than the girls (56.67 %). Girls are punished (38.33 %) more often than the boys (27.40 %). Parents report various types of burdens like disciplining and management of problem behaviors -97 %, being upset about comparison with other children - 94 %, apprehensions about
improvement in the child - 89%, social embarrassment - 79 %, social isolation - 68 %, extra time - 54 %, reduced leisure time - 52 %, financial problem - 51 %, daily care stress - 35 %, effect on sibs - 24 %, family disputes about the retarded child - 8 %. The spouse is reported by a majority of parents as the greatest source of emotional support (65.17%) followed by supports from their own parents and sibs (40.45 %) and professionals (12.36%).

(2) Studies on Behaviour Disorder

Peshawaria, Venkatesan & Menon (1990) studied 300 cases of mentally handicapped persons with behaviour problems. 12 areas of behaviour problems are identified. They are – physical harm, damaging property, misbehaving with others, temper tantrums, wandering, disobedience, repetitive behaviours, restlessness or physical over activity, odd behaviors, fears and sexual problems. Parents predominantly seek help for managing problems of disobedience (15.8%) and the least perceived behaviour problem is in the sexual area (0.9 %). This could be more due to inhibitions in parents to openly report on such matters.

In terms of severity of retardation the trends appear to be similar for the mild and moderate groups where disobedience and physical harm are perceived as major problems. Odd behaviours are perceived more commonly in severe and profound groups. With age, behaviour problems decrease. Wandering is more in males and temper tantrums and fears are more in females. Parents from both nuclear and non-nuclear families perceive disobedience as the major problem. Parents from urban setup report more behaviour problems related to disobedience whereas parents from rural setup report greater frequency of physical harm.

Peshawaria, Venkatesan, Mahaputra and Menon (1990) surveyed 288 institutions out of which 148 institutions with 530 teachers responded to the "The Problem Behaviour Checklist" mailed to them. Reliability for the behaviour problem checklist is 0.68. The teachers perceived various problem behaviours such as restless and physically overactive behaviour (86.23%), inattentive (84.53%), misbehaves with others (66.96%), physical harm towards others
(63.83%), odd behaviours (60.96%), temper tantrums (58.75%), rebellious behaviours (55.51%), damages property (55.52%), repetitive behaviours (52.28%), self injurious behaviours (46.90%), fears (43.64%), antisocial behaviours (39.26%). Teachers perceive problem behaviours predominantly in the form of restless and physically over active, inattentive behaviours, and misbehaving with others. They perceive it least in the areas of self-injurious behaviour, fears and antisocial behaviours. Experienced (0 to 5 years of experience =303, 5+ to 10 years = 137 and 10+ = 90) and trained (teachers = 287 and untrained = 243) teachers perceive more number of behaviour problems (P < 0.01).

Padencheri & Russell (2002) compared the level of hope among parents of children with and without challenging behaviour. The participants were 46 parents (mean age 33 years) of children (mean age 5.6 years) with multiple, single and no challenging behaviours. These three groups were compared for their total and subscale hope scores with analysis of variance. Multiple regression analysis was applied with the total hope score as the dependent variable. The results show that hopelessness is related to challenging behaviour. The post hoc test shows different levels of hopelessness between parents in challenging behaviour groups in relation to the control group. In particular, only the parents of intellectually disabled children who have multiple challenging behaviours have significantly lower hope scores than the other two groups.

(3) Studies on Siblings

Saxena and Sharma (2000) examined the sense of well being of adolescents who had younger siblings with mental retardation; investigated the current pattern of interaction between adolescent subjects and their mentally retarded siblings; and studied gender differences in the adolescents' self-esteem in a 1997-98 study. The sample comprised of 15 adolescent siblings (7 boys and 8 girls) of mentally retarded children in the age range of 12-18 years. Tools used were an interview schedule, Coopersmith Self Esteem Inventory, "My Sibling and
I" statements and Indoor games. The findings reveal that a majority of the siblings (12 out of 15) have "medium" level of self-esteem. Their sense of identity is not negatively influenced by the presence of a disabled brother/sister. However, there are significant differences in the self-esteem of boys and girls. Male siblings have higher self esteem than females. The relationship between the 2 siblings seemed to be comfortable. The adolescents (13 out of 15) are well adjusted in their sibling role and had accepted the disabled sibling as an inseparable part of their lives. Peer relationships of the adolescents are not altered by the presence of a disabled sibling though there are signs of latent shame associated with having a "different" sibling (5 out of 15). A majority of subjects (8 hoped to give physical support and 6 hoped to give economic supports) expressed their willingness to take future responsibility of the child.

Singhi, Malhi & Pershad (2002) studied the impact of disabled child on the psychosocial adjustment and self concept of siblings in the family by comparing 76 siblings of normal children with 75 siblings of children with cerebral palsy and 25 siblings of children with mental retardation from demographically matched families. Tools used were semi-structured questionnaires, Pre-Adolescent Adjustment Scale, Children's Self Concept Scale, Malin's Intelligence Scale for Children and Socio-Economic Status Scale. No significant differences are found between the siblings of disabled children and those of healthy children on measures of psychosocial adjustment [F (2,173) =1.58 NS], self-concept ratings [F (2,173) =1.16 NS] and intelligence [F (2,173) =1.02 NS]. Overall, the results fail to support the proposition that siblings of disabled children are at greater risk for developing psychosocial adjustment problems.

(4) Studies on Coping

Ghatak & Indiresan (1983) studied 44 (15 girls and 29 boys) educable mentally retarded children by using the Family attitude questionnaire and the IPAT anxiety scale. They find that the significant factors (Chi-square values are given in the brackets) which are important and conducive for the educable mentally retarded
children are parent's positive goal oriented behaviour towards the psychosocial growth (12.81), positive movement towards rehabilitation (12.70), high levels of marital integration (22.41), favourable and nurturing attitude of the normal siblings (10.59), positive sibling parent interaction (26.53), positive family interaction with the retarded child (13.13), positive social participation of the retarded child (14.72), acceptance of life pattern changes after birth of the retarded child (12.74) and supportive social environment (14.07).

Master (1991) conducted a five year case file study of 113 mentally retarded children (7-10 years =47, 11-15 years = 42 and 15-20 years = 24) with associated mental illnesses (Hyperkinetic =18, Childhood schizophrenia = 6, Emotionally unstable = 41, Anxiety with occasional panic = 28, Masturbation = 3, Asocial behaviour = 8 and Epilepsy = 9). Psycho-pharmacological treatment, behaviour therapy and counseling were used in treating theses individuals. Results indicate that 61 had good improvement, 33 had moderate improvement and 19 had no improvement. Management of these mental illnesses helps parents to plan their children's future in a better way.

Venkatesan (1999) elicited parental (34 fathers and 11 mothers; totally 45 parents) perception of adjustment patterns in a sample of 45 adults (IQ 50-69; Age 16-39 years; 32 males and 13 females) with mental retardation. Telugu translation of Bells Adjustment Inventory-Student Form was used. Parametric tests were used for analysis of data. Fathers appear to perceive significantly greater number of adjustment problems in their mentally retarded children (mean=44.24, SD=16.72) compared to mothers (mean=28.27, SD=7.86). This difference is significant at 0.01 level for areas of home and at 0.05 level for emotional adjustments. Parent's education or sex of the handicapped child is not significantly related to perceived adjustment.