REVIEW OF LITERATURE
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In recent years researchers and interventionists have become interested in parents and families of children with mental retardation. The concentration has been towards mothers and fathers who serve as the back bone for care, treatment and rehabilitation of these children. Much research has been undertaken on various aspects of family dynamics of such families. A review of literature related to these aspects has been presented in this chapter.

STUDIES RELATED TO FAMILY STRESS:

Parenting itself can be generally a stressful life event, (Giband, Wallston and Wandersman, 1978) and the manifestation of major and child problems may be the most significant of stress across a range of unpleasant parental effects. Many of the behaviours commonly exhibited by problem children are perceived by parents as annoying, noxious and stressful (Jones, Reid and Patterson, 1975).

Cummings (1976) compared the psychological adjustment of fathers of mentally retarded with chronically ill and healthy children. Results indicated that the fathers of mentally retarded had more depressive feeling and more pre-occupation with the child. They exhibited more inferiority as fathers and had general lack of relationship gratification with low enjoyment of the child. The fathers had greater negative impact from fathering than those of chronically ill children.

Beckman’s (1983) focus of study was to examine the relationship between child characteristics and stress reported by mothers. The child characteristics considered were rate of development, social responsiveness, temperament, repetitive, stereotypic behaviours and additional care giving demands. The results of Beckman indicated that four of the child characteristics, temperament, responsiveness repetitive behavioural patterns and care-giving demands, were significantly related to the amount of stress reported by the mothers. Single parents experienced more stress.

Moudgil et al., (1985) had undertaken an investigation to understand the quantum of stress on the parents of mentally retarded children. Social and emotional support systems adopted to cope with the stress; the interpersonal relations of the
parents and the social image of the family are affected in the community because of the retarded child

It is found that because of the mentally retarded child in the family, parents were depressed most of the time, worry about getting their children admitted to school, pairs to pay more attention to retarded child, and their marital harmony and relations with their family members are disturbed. The social image of the parents is also affected. It was found that those parents who get maximum social and emotional support from spouses, family members, parents, relatives and friends experience less stresses and problems as compared to those parents who are not getting much social and emotional support. It was also found that the parents could not achieve some of their life goals and when the child was female it created more social and emotional problems.

The results suggested that stress levels are somewhat elevated in families with pre-school children, the tendency being particularly marked in families with intellectually handicapped children. The implications of these findings for family intervention and support programmes are considered, together with the need for research into the various ecological contexts of the individual, family, peer group and social institutions.

Mothers and fathers of 125 handicapped/chronically ill children were compared with parents of 127 matched non-disabled children from three separate samples with respect to personal stress, marital satisfaction, and social network size and density in a study conducted by Kazak (1987). Only mothers of disabled children experienced higher levels of stress than comparison parents. No differences were found in marital satisfaction. Few group differences were found for social network variables, although mothers of handicapped children had higher-density networks than comparison mothers

Donovan (1988) investigated the mother's perceptions of family stress and ways of coping with adolescents who were autistic or had mental retardation. Results indicated group differences among maternal reports of family stress. All comparisons of child related stress revealed that mothers with an adolescent who was autistic perceived greater level of family stress than did mothers with an adolescent who had mental retardation. Marital adjustment did not differ by group. Further, maternal
coping styles were consistent across groups, indicating that mothers with adolescent who had a handicap relied heavily on community resources and professional help for coping. The findings suggested that when the demands associated with parenting adolescent with handicaps exceed the resources of the family, mothers choose to cope by actively seeking support, advice and help outside the family system.

Flynt and Wood (1989) examined the perceptions of family stress and coping behaviour of ninety (90) mothers with a moderately mentally retarded child. Preliminary analysis showed no significant differences in effects of either interaction on maternal perception of family stress or coping behavior. Child's age did not significantly affect the stress and coping scores. Black mothers reported lower perceived family stress than did white mothers and reported higher scores on coping. Health Inventory indicating greater utilization of coping strategies centered on intrafamily resources and social support. Older mothers reported lower perceived family stress than did young mothers.

Frey et al., (1989) examined the mediating influences of child characteristics, social network, parent beliefs and coping styles on parenting stress, family adjustment and psychological distress of mothers and fathers. Subjects were forty eight (48) mothers and forty eight (48) fathers of young children with handicaps. The age of the handicapped children ranged from 32 months to 168 months Results indicated that child characteristics predicted mother’s and father’s parenting stress and father’s psychological distress. Parental belief systems predicted all three parent outcomes for mothers and fathers. Coping styles predicted psychological distress and father’s family adjustment. Social network predicted family adjustment and father’s psychological distress. Psychological distress was low in mothers who had either a positive belief system or a non-critical family network.

Crnic and Greenberg (1990) explored the minor parenting stresses among seventy four (74) mother child pairs participating in a longitudinal project. At the time of the study the children’s age was five years. Analysis indicated that life stress and parenting daily hassles significantly predicted aspects of child, parent and family status. Hassles, however, proved to be a more powerful stress construct. Further analysis
indicated that mother’s social support moderated the influence of hassles on indices of maternal behaviour.

Studies were carried out by Dytrych et al (1991) in a series of 100 mothers of children with facial clefts who were treated up to the age of 13 to 15 years at the Department for Plastic Surgery. Results showed that three quarters of mothers designated the birth of a handicapped child as a mental shock followed by a variety of neurotic symptoms. A certain proportion of mothers suffered from reactive depression which was not diagnosed and therefore not treated.

Baxter (1992) investigated the impact of perceptions on stress experienced by parents of children with intellectual disabilities. Sample comprised of 60 parents of 3-5 years old children, 35 parents of 10-12 years old children and 36 parents of 17-19 years teenagers. Parental stress attributed to care and management of the child with an intellectual disability was found to be related to the extent of child’s dependence and the extent of child’s behaviour problems. An interesting finding of the study is the curvilinear pattern of relationship between stress and the appraised significance perceptions across the three age categories.

Rousey et al., (1992) commented about stress in families with children who have special needs. Fifty one (51) mothers and forty two (42) fathers constituted the sample. The results of the factor analysis did not reveal overwhelming differences between factors and between parents mean scores. Gender of the parent seems to have minimal effect on perceptions of stress and coping.

Orr et al., (1993) studied stress experienced by families with a child who has developmental delay. Mothers with children ranging in age from 2 to 18 years were assigned to a pre-school, middle childhood group and the adolescent group. Results indicated that children belonging to all the three groups were strong sources of stress for mothers. The second trend that is evident was that mothers in the middle childhood group reported consistently higher stress scores than did mothers in the other two groups on both parent and child Domain Scores.

Psychological distress, as expressed through symptoms of depression, was studied by Trute (1995) in a cross-sectional sample of parents providing homecare to
developmentally disabled children. Mothers and fathers were interviewed separately in 73 households. The intent of the study was to explore predictors of symptoms of depression to better understand what child, family and life circumstances might be differentially related to psychological stress in the cohorts of men and women. Mothers with younger children, and fathers with male children, appeared to be at higher risk for depression. Personal or intra-psychic coping resources (self-esteem) and strong-tie social support resources (spousal relationship) were found to be significant predictors of depression in both mothers and fathers. Informal respite resources were related to mothers' well-being.

Grieving is an ongoing feature of parenting children with intellectual disability, (Bruce et al 1996) used measures to define the presence of grief over time. It was also found that the 49 mothers and 49 fathers reported similar intensity of continued wishing for what might have been. The responses of the mothers to current levels of distress when thinking about time of diagnoses are significantly more intense than those of the fathers.

The research by Hodapp et al (1997) examined family stress and sibling reactions in families of children with cri du chatt syndrome, aged 1 to 18 years who were living at home. The best predictor of familial stress was the child's amount of maladaptive behavior.

The results of a study by Browne & Bramston (1998) into stress and quality of life in the parents of young people with an intellectual disability finds that parents suffer stress as a result of having a son or daughter with an intellectual disability. To describe stress and coping in families of children with Smith-Magenis syndrome, Hodapp et al (1998) interviewed and received questionnaires from families of 36 children with this disorder. It was found that the stress levels of the families of children with Smith-Magenis syndrome were higher.

The study by Stores et al (1998) investigates the occurrence of daytime behaviour problems and maternal stress in a group of children with Down's syndrome (DS). The children with DS and the children with other intellectual disabilities showed significantly higher rates of behavioural disturbance. Maternal stress was significantly higher in the group with other forms of intellectual disability.
The purpose of a study by Sigaud (1999) was to understand the experiences of a mother of a Down syndrome child. The subjects were nine mothers of Down syndrome patients between the ages of six and twelve. The mother experienced ambivalent feelings and behaved in an overprotective way.

The adaptation of parents to a disabled infant was studied in relation to the type of disability by Pelchat et al (1999). Participants were divided according to three types of disability and one control group: patents of infants with (1) Down's syndrome (DS), (2) congenital heart disease (CHD), (3) a cleft lip and/or palate (CLP), and (4) no disability (ND). The data were collected to measures parenting stress, stress appraisal, and psychological distress. Results indicate that parents of infants with DS and parents of infants with CHD report greater levels of parenting stress and psychological distress. Mothers were found to report greater levels of stress and distress overall.

Ong et al (1999) conducted a study to compare parenting stress among Malaysian mothers of children with mental retardation and a control group, and to determine factors associated with stress. Seventy-five mothers of children with mental retardation aged 4-12 years and 75 controls (those without disabilities who attended the walk-in paediatric clinic) participated in the Parenting Stress Index (PSI). A large proportion of mothers of children with mental retardation experienced substantial parenting stress, especially Chinese and unemployed mothers.

The study by Warfield et al (1999) documents the extent to which child-related and parenting stress vary during the early childhood period among mothers of children with developmental disabilities. The degree to which specific aspects of the family environment predict stress levels measured at age 3 years and 5 years, after controlling for child characteristics and family income is also investigated. The Parenting Stress Index was completed by 79 mothers of children with developmental disabilities Child-related stress increased significantly, whereas parenting stress remained fairly stable. Greater family cohesion and fewer negative life events predicted lower stress scores. There was significant increase in child-related stress during the early childhood period.

Hall et al (2000) conducted a study to determine the psychological consequences for parents of children with Down's syndrome who have received a false negative result on prenatal screening, with that of parents not offered a test and those
who declined a test. Regardless of screening history parents adjusted well to having a child with Down's syndrome. Compared with mothers who declined a test, mothers in the false negative group had higher parenting stress more negative attitudes towards their children. Fathers in the false negative group had higher parenting stress test scores than fathers not offered a test. Mothers in the false negative group were more likely to blame others for the outcome than mothers who had not been offered the test. Mothers and fathers in the false negative group were more likely to blame others for this outcome than parents who had declined a test. Blaming others was associated with poorer adjustment for mothers and fathers.

The influence of employment on parenting stress among mothers of 5-year-old children with developmental disabilities and the influence of parenting demands (i.e., caregiving difficulty and behavior problems) and family support on their work quality and absenteeism from work was examined by Marji (2000). No significant associations were found between employment status and parenting demands, family support, or stress for the sample as a whole.

Perceived changes in well-being of parents with a child in a therapeutic toddler class were studied by Hendriks et al (2000). Parents perceived a positive change in well-being 10 months after their child started visiting the therapeutic toddler class. Mothers as well as fathers said to have gained more insight in their child's abilities and to feel less that they are all on their own. The impact of the toddler class program on well-being was greater for mothers than for fathers, especially with respect to feeling fit, planning social activities, and having time for their own relaxation. Fathers, however, gained more insight in the abilities of the child than mothers did after ten months.

The influence of employment on parenting stress among mothers of 5-year-old children with developmental disabilities and the influence of parenting demands (i.e., caregiving difficulty and behavior problems) and family support on their work quality and absenteeism from work was examined by Warfield (2001). No significant associations were found between employment status and parenting demands, family support, or stress for the sample as a whole. Among employed mothers, those who rated their jobs as interesting reported significantly less parenting stress when they
experienced low or mean levels of parenting demands. Mothers' interest in work did not moderate the negative influence of high levels of parenting demands on stress. Parenting demands increased absenteeism but had no effect on work quality.

Using measures of child and family functioning, Smith et al (2001) studied the parenting stress in families of children with disabilities. The levels of parenting stress in 880 families of children with disabilities suggest that factors such as income, time available for interaction with the child, and social support predict parenting stress much better than do aspects of child functioning.

Moderators of stress in parents of children with autism was studied by Dunn et al (2001). Parents of children with autism experience more stress and are more susceptible to negative outcomes than parents of children with other disabilities. They examined the relationship between stressors, social support, and locus of control, coping styles, and negative outcomes (depression, social isolation, and spousal relationship problems) among parents of children with autism. It was found that several coping styles corresponded to negative outcomes. Furthermore, the relationship between stressors and negative outcomes was moderated by social support and coping style.

The cognitive and adaptive behavior development of children with developmental disabilities and the adaptation of their parents, extending from infancy through middle childhood were studied by Hauser et al (2001). Children's type of disability also predicted changes in maternal (but not paternal) child-related and parent-related stress. Beyond type of disability, child self-regulatory processes (notably behavior problems and mastery motivation) and one aspect of the family climate (notably mother-child interaction) were key predictors of change in both child outcomes and parent well-being. A different aspect of the family climate--family relations--also predicted change in child social skills. Parent assets, measured as social support and problem-focused coping, predicted change in maternal and paternal parent-

Parental depression was assessed by Olson & Hwang (2001) using the Beck Depression Inventory (BDI) in 216 families with children with autism and/or intellectual disability (ID). Mothers with children with autism had higher depression scores than mothers of children with ID without autism, who in turn, had higher
depression than fathers of children with autism. Forty-five per cent of mothers with children with ID without autism and 50% of mothers with children with autism had elevated depression.

In a study conducted by Baker et al (1991) early evidence of behavior problems in 225 three-year-old children with or without developmental delays and the relative impact of cognitive delays and problem behaviors on their parents were examined. Children and adolescents with mental retardation are at heightened risk for mental disorder. Parenting stress was higher in delayed condition families. Analyses revealed that the extent of child behavior problems was a much stronger contributor to parenting stress than was the child's cognitive delay.

Hedov et al (2002) conducted a study with Swedish parents of children with Down's syndrome. Becoming parents of a child with Down's syndrome (DS) challenges the adjustment ability in parenthood. Individuals with higher sense of coherence (SOC) are supposed to manage stressors better than those with lower SOC. The aims of this study were to investigate parental self-perceived stress, SOC, frequency of gainful employment and amount of time spent on child care. The DS parents did not spend more time on child care, but the DS parents perceived greater stress. Parents with high SOC scores experienced significantly less self-perceived stress.

A study by McGlone et al (2002) focuses on the nature and extent of parental stress among adoptive parents of special-needs children. Results indicated higher than average levels of stress, particularly on subscales related to parent-child dysfunctional interactions and to raising a difficult child. Increased stress levels were associated with poorer family adjustment and with higher levels of child behavior problems. Stress levels remained mostly unchanged over the year. Responses to open-ended questions identified five stress categories: child characteristics, parent-child interactions, family cohesion, parental adjustment, and adoptions service issues.

The aim of the study by Firat et al (2002) was to evaluate anxiety, depression, and general psychological symptoms in the mothers of autistic children in comparison with those in the mothers of mentally retarded children. Forty mothers of autistic children and 38 mothers of mentally retarded children were included in the study. Non-
depression rates was 27.5% in the mothers of autistic children whereas the rate was 55.3% in the mothers of mentally retarded children. There was no difference regarding anxiety between the two groups. The mothers of autistic children experienced more psychological distress than those of mentally retarded children.

Not only do parents experience stress but persons with intellectual disability also undergo stress. There is evidence that people with ID are more vulnerable to stress and use less effective coping strategies. (Janssen et al. (2002)

STUDIES RELATED TO COPING:

The following review may help one to identify the various coping styles and strategies employed by the individuals in the families.

Friedrich et al., (1985) used a multidimensional and longitudinal framework for studying coping resources and adjustment in families with a child who has mental retardation. It was hypothesized that four dimensions of coping resources; utilitarian, health / energy / morale, social support and belief systems as well as child characteristics would predict parenting outcome. Changes in marital satisfaction were related to an increase in parent and family problems.

Cole (1986) provided a theoretical framework for understanding the relation between family stressors, family resources and child placement. In-home versus out-of-home placement is regarded as one index of family adaptation. Stressors related to the child’s handicapping condition combine with the family’s pre-existent stressors to produce crisis. Faced with excessive demands, the family may cope by eliminating the stressor which is nothing but placing the child out-of-come.

Kravertz et al., (1993) examined how mothers and fathers cope with tensions involved in the day-to-day struggle of raising a child with mental retardation. Further more, it was investigated whether the ways in which mothers and fathers cope with these tensions are related to the school adjustment of the child. Mother’s problem focused coping correlated positively with their children’s constructive behaviour and negatively with their children’s behaviour disturbance. Although a statistically significant difference was found between mother’s and father’s use of coping strategies, this differences does not seen to be a consequence of the relations between mother’s
and father’s coping strategies and particular aspects of their children’s school adjustment. Fathers reported using emotion focused coping less often than did mothers even though, a statistically significant relation was discovered between fathers emotion focused coping and their children’s school achievement.

While reviewing the literature on stress and coping in families of developmentally handicapped children Tunali &Power (1993) proposed an alternative way for conceptualizing some of the psychological processes involved. The approach specifies how a threat to certain human needs lead to predictable patterns of appraisal and coping.

Tung and Jagijit (1994) conducted a study to see the sex differences on a measure of coping strategies. Two hundred (200) students (100 male and 100 female) were studied using the coping operations preference enquiry. The males used the coping styles of “Denial” (a coping style in which the individual denies of having any stress) and “Isolation (a tendency to be less emotional and face the situation more intelligently).” Females were significantly high on turning against self-a pattern in which the individuals is fully aware of the stressful even but considers herself incompetent to face it and holds oneself responsible for it.

Beresford (1994) considered the ways parents cope with the chronic strain and daily stressors associated with caring for and bringing up a disabled child. Coping resources—both personal and socio-ecological—have been described, and the notion of vulnerability when resources are not available has been considered. The relationship between coping strategies and adjustment was explored.

The purposes of the study conducted by Heaman (1995) were to describe perceived stressors and coping strategies of parents who have children with developmental disabilities and to examine similarities and differences of mothers and fathers in their perceptions of stressors and coping. Stressors and coping strategies were identified. The stressor reported by the largest number of both mothers and fathers was concern about the child's future. There were fewer differences between mothers and fathers in reporting of stressors than in reporting coping strategies.
Coping and correlates of psychological distress of Chinese parents of children with Down syndrome were examined and compared to parents of children with language delays or no disabilities by Cheng&Tang (1995). Individual parent scores were used for analyses, with groups and gender of child and parent as independent factors. Down syndrome group parents reported the most frequent use of avoidance coping style, followed by parents of the language delay and no disabilities groups. Compared to parents in the no disabilities group, the other parents reported a higher level of psychological distress, were less optimistic, felt less self-efficacious, and engaged in more frequent use of self-reliance coping style. Main effects for parent gender revealed that mothers engaged in more frequent use of self-reliance, avoidance, and seeking social support coping styles. Mothers also reported a higher level of distress but lower levels of optimism and self-mastery.

Pisula (1996) studied the relationships between coping with stress and well-being in mothers of developmentally disabled children. Marital, parenthood and global life satisfaction were analyzed. A significant relationship between coping strategies and well-being (marital and global life satisfaction) were found.

In a study conducted by Dyson (1997) thirty pairs of fathers and mothers who had school-age children with mental retardation and other disabilities were compared with each other and with 32 father and mother pairs of parents of children without disabilities. Responses to family scales indicated that fathers and mothers of children with developmental disabilities did not differ from each other nor from fathers and mothers of children without disabilities in parental stress, family social support, or family functioning. However, parents of children with disabilities experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities. Fathers' and mothers' stress was associated with aspects of family functioning as perceived by themselves and their spouses.

The aim of the study conducted by Vanden Borne et al (1999) was to identify the psychosocial problems of parents of a child with Prader-Willi syndrome or a child with Angelman syndrome. In addition, the strategies these parents apply to cope with these problems as well as their need for information are described. Both parent groups
were found to have a high need for information, high feelings of loss of control, relatively high depressive feelings, particularly in mothers in both syndrome groups.

Hope helps in coping among parent with intellectually disabled children. However, it has been studied little in relation to challenging behavior in these children. This study by Padancheri & Russell (2001) compares the level of hope among parent of intellectually disabled children with and without challenging behaviour. Hopelessness was related to challenging behaviour. Parents of intellectually disabled children who had multiple problem behaviours had significantly lower hope scores than the other two groups. More than one challenging behavior may be a risk factor for hopelessness among parents of children with intellectual disability.

The study conducted by Richard & Helen (2001) stresses the importance of asking more positive questions about the perceptions and experiences of families of children with developmental disabilities. Positive perceptions function as strategies that help families adapt to or cope with the experiences of raising a child with disabilities.

Kearney PM, and Griffin T. (2001) studied joy and sorrow of being a parent of a child with developmental disability. This study explored the experiences of parents who have children with significant developmental disability. Whilst parents confronted numerous difficulties, most of them appeared to manage with optimism and remarkable resourcefulness. Although they experienced much anguish and sorrow, the parents also spoke of hope, love, strength and joy. Interpretation of the parents' experiences revealed the themes of 'joy and sorrow', 'hope and no hope' and 'defiance and despair', mediated by 'the tensions'.

McIntyre et al (2002) studied the impact of dual diagnosis [i.e. intellectual disability (ID) and mental disorder] in young adults on their mothers' perceived levels of stress and decisions about placement. The mothers of young adults with severe ID were interviewed to assess their child's adaptive functioning, maladaptive behavior, mental health problems and negative impact on the family. Behavior and mental health problems (B/MH) significantly predicted the mothers' perceived negative impact of the young adult on the family, even after controlling for other young adult characteristics. These problems also predicted the family's steps toward seeking out-of-home placement.
The study by Taanila et al (2002) was to clarify how families with physically and/or intellectually disabled children cope, the kind of coping strategies they use and how the families with good and poor coping capacities differ. Parents of eight children (aged 8-10 years) with physical and/or intellectual disability were interviewed twice. Information and acceptance, good family co-operation and social support were related to the coping strategies most frequently used. Half of the families seemed to have found successful ways of coping, whereas another half had major problems. There were five main domains in which the high- and low-coping families differed most from each other: (1) parents' initial experiences; (2) personal characteristics; (3) effects of the child's disability on family life; (4) acting in everyday life; and (5) social support. By recognizing the coping strategies used by the family, professionals and service providers can find the right ways to support their adaptation.

Chinese mothers' experiences of parenting a child with Down syndrome were explored by Lam & Mackenzie (2002) Seven major themes were identified: unexpected birth of an abnormal child, acceptance of the child, special needs of the child, worry about the future, knowledge deficit, effect on the marital relationship, and social restrictions. The types of stressors changed over time according to the child's age, and coping strategies varied accordingly. Strategies frequently used were avoidance, self-reliance, and seeking social support.

Impact of residential placement on families was studied by Baker & Blacher (2002) Post placement adaptation was studied in 106 families with a member living in a residential facility. Respondents reported on three broad areas of functioning: involvement with the member in placement, well-being, and perception of placement advantages and disadvantages. Although respondents readily reported both pros and cons of placement, more than 90% concluded that, the living arrangement was an advantage for themselves, the child, and other family members. Families with children under age 15 often reported the highest stress and caretaking burden, as well as the lowest marital adjustment and advantage to placement.

Research conducted by Little (2002) on families of children with disabilities shows that family cohesion and positive family outcomes are influenced by how mothers and fathers cope with raising their child with disabilities. This study was
designed to examine stress and coping differences between mothers and fathers (n = 103) of children with Asperger's syndrome (AS) and nonverbal learning disorders (NLD). Responses indicated that mothers had higher rates of stress related to family problems and pessimism about their child's future, higher rates of antidepressant use, and higher rates of therapy use than did fathers. Mothers found some coping strategies more helpful than fathers did. Maternal education and child's age also were related to some stress and coping variables.

The relationships between feelings of loneliness, social support and psychosocial adjustment, and the influence of gender and family size on psychological adjustment of siblings of children with autism were examined by Kamininnsky & Dewey (2002). It was found that large family size appears to facilitate healthy adjustment in siblings of children with autism.

Sullivan (2002) conducted a research on the reactions of parents, and fathers in particular, following the birth of a child with Down syndrome. It was found that gender differences exist in coping strategies. Mothers scored significantly higher than fathers in seeking instrumental and emotional support; in focusing on and venting emotions; and suppression of competing activities.

**STUDIES RELATED TO FAMILY BURDEN:**

Goldman as long back as 1962 considered family member whose social functioning is inadequate or affected will lead to greater family burden. The existence of burden indicates the breakdown of reciprocal arrangements that people maintain in their relationships, so that, some persons in the family have to do more than their fair share. Since they do more than what they have to do, their activities are often restricted.

The term family burden can be defined operationally as the extent of suffering experienced by the family of mentally handicapped child due to various problems encountered with regard to financial conditions, routine family interaction, leisure, physical and mental health of other members of the family caused by the handicapped family member. Hatfield (1987) has pointed out that the effect of mental illness on the family is affected by three major variables.
1. Where the ill person lives and who is charged for responsibility for his or her care;

2. The meaning of the illness to the family and especially the way in which that meaning is influenced by prevailing theories of etiology;

3. The degree of understanding, compassion, and support given to affected families and the skill and appropriateness of help offered by the community.

This is true of families with mentally retarded children also. There are multiple sources of stress that create a burden for the caregivers-situational, societal, and iatrogenic.

Constant stress may be often viewed as a burden. The following studies indicated how the families felt it as a burden to raise a child with mental handicap.

Jain and Satyavathi (1969) opined that the presence of a child with mental handicap can become a source of continuous stress and burden on family members.

Dupont et al. (1980) reported that in 80% of the cases, the parents' sleep was disturbed by the child, 59% of the mothers had given up or limited their cultural activities, 77% had limited contact with friends, 49% had limited contacts with relatives and 59% had stopped going on vacation. Sixty seven percent of the families stated that the circumstances altered.

Bernheimer LP, et al (2003) in a study on impact of children with troubles on working poor families, found that sixty percent of families had at least one child who had significant problems (learning, school achievement and/or behavior, home behavior, retardation, and other disabilities). There is less family adaptation specifically in response to the troubled child, and there was more struggles of making ends meet.

Disruption in family leisure and effect on mental health of the mother were reported more often by the mothers of female children, as compared to those of male children. Rest of the categories of burden revealed no significant differences between the mothers of boys and girls. The perceived social burden was felt the maximum in family activities and family interaction. (Tangri & Verma 1992)
A survey by Leonard et al (1993) was mailed to caregivers of children with disabilities to ascertain how they were managing care giving. Caregivers reporting they were managing "OK" were compared to those who reported they needed more help or could not manage much longer ("not OK"). Results showed the not OK group of caregivers had children who were more severely impaired and functionally dependent. Their mothers were in poorer physical and mental health, had greater demands placed on their time and finances, and received less emotional support from friends and family. Special programs provided some assistance but not enough to meet their needs.

Factors related to families' perceptions of internal resources when raising children with developmental disabilities were examined by Herman & Thompson (1995). Families enrolled in a Cash Subsidy Program were surveyed about their resources, use of services, and helpfulness of social supports. Parents saw their basic resources for daily life as adequate. However, they reported that their time, discretionary money, and child-care resources were not adequate for caring for their children. Helpfulness of social supports, the children's characteristics, and income were related to perception of resource adequacy. Findings suggest that support services must be flexible in the types and amounts of services provided.

In a study conducted by Carpiniello et al (1995) twenty parents of mentally retarded children and 20 parents of children with neurological impairments were interviewed to determine their levels of psychiatric symptoms and of subjective and objective burden associated with care for their disabled child. The parents of disabled children had significantly higher levels of psychiatric symptoms and were more likely to meet criteria for depressive disorders, compared with a matched control group of parents of children without disabilities. The two groups of parents of disabled children reported considerable subjective and objective burden, although there were no differences between those groups in the level of burden.

Effects of children with Down syndrome on parents' daily activities were investigated by Barnett & Boyce (1995). Data on the allocation of time to daily activities were obtained from time diaries provided by two samples of parents with at least one child under age 17. Parents in one sample had a child with Down syndrome and parents in the other sample did not. Comparison of time allocations by sample
indicated that parents of children with Down syndrome differed substantially from other parents in their patterns of time use. Both parents of a child with Down syndrome devoted more time to child care and spent less time in social activities. Mothers of children with Down syndrome allocated less time to paid employment.

This article "What will happen to my child when I'm gone?" A support and education group for aging parents as caregivers by Mengel et al (1996) describes the rationale, design and implementation of a support and education group for parents caring for disabled children in later life. In a supportive and informative environment, parents found peers facing similar challenges relating to the provision of care in light of their own aging, a lifetime of caregiving, and their concerns about their children's futures. The experience of this group intervention strategy provides insight into the needs and strengths of this neglected segment of the caregiving population.

Interviews with parents of adult children with mental retardation were conducted by McDermott et al (1997) to identify differences in caregiver burdens and gratifications, based on in-home and out-of-home placement. Parental responses indicate that caretakers of adult children with mental retardation are worried and feel responsibility for their care regardless of residential placement of the adult child.

Chronic sorrow and the life experiences, memories, and opinions of two health care professionals who are the parents of a profoundly mentally retarded adult child were studied by Krafft & Krafft (1998). The parents' experiences confirm the lasting nature of chronic sorrow. This sadness without end continues to be a force in the lives of these parents.

The relation between child characteristics and parents' developmental expectations for their children with developmental delays at ages 3, 7, and 11 was examined by Clare et al (1998). Parents' developmental expectations were moderately stable over time, tending to decline as children matured.

A study of the adjustment difficulties and needs of 70 adults with Williams syndrome by Udwin et al (1998) found that the majority continued to live at home and remained heavily dependent on their families for their self-care. In the majority of cases, families continued to shoulder the main burden of care for their sons and
daughters with Williams syndrome well into adulthood, with little support from statutory and voluntary agencies

The study by Llewellyn et al (1999) explores the factors which influence families to care for their children at home or to place them out-of-home. Everyday family life experiences of 167 families of young children with a disability and high support needs were studied. One hundred and twenty-five (75%) of these families definitely did not want to place their child, 32 (19%) were undecided, and 10 (6%) were actively seeking or had already sought placement.

The impact of disability- and risk-related characteristics of 166 infants on their mothers' employment and child-care characteristics and decisions was investigated by Booth & Kelly (1999). Mothers' employment plans and child-care decisions were affected by their children's special needs (chronic health problems; use of adaptive equipment; total risks; diagnosis; and mental, motor, and adaptive functioning).

Data regarding future residential plans were collected from 141 mothers of adult children with mental retardation in a study by Pruchno & Patrick (1999). Results demonstrate that greater caregiving burden was associated with more extensive planning for residence within the formal service system and less planning for residence with a family member. Planning for residence with a family member and higher functional ability on the part of the child significantly decreased the sense of worry mothers had about the child's future whereas plans for the child to reside within the formal system had no association with worry about the future.

A cross-sectional survey was conducted by Chen et al (2001) to describe the health of mothers of adults with intellectual disability (ID), and the influence of the mother's and her adult child's characteristics on her health. The sample consisted of 108 mothers divided into mid-life and later-life groups. Arthritis was found to influence the physical health of both groups of mothers. Employment was found to influence physical health of the mid-life mothers, while family income was found to influence mental health of the later-life mothers. The characteristics of adults with ID did not influence the mothers' health significantly. Mothers' caregiving for their adult children with ID might not be as detrimental to the mid-life mothers' physical component of health as it might be to the later-life mothers.
Burden among caregivers of children with intellectual disability was studied by Datta et al (2001). This study determines the pattern of demographic, caregiver and child characteristics that specially predict burden among the primary caregivers of children with intellectual disability in India. 31 families with an intellectually disabled child, were assessed. Results predicted a high level of burden among the caregivers. These results reinforce the importance of expressed emotion, perceived prognosis about disability and age of the disabled child in predicting burden among caregivers of children with intellectual disability and thus a focused intervention.

15 families with autistic children, 15 with Down's syndrome and 15 asymptomatic children were studied for family dynamics by Sprovieri & Assumpcao (2001). Patients' age ranged from 5 to 15 years-old. The parents of these three families' groups were apprised in regard to their family dynamics, to relate those symptoms to the functioning of their families. Autistics' families and victims of Down's syndrome made it difficult to sustain the emotional health of group members.

Some of the studies so far reviewed in this section reported effect of burden on families with children with disabilities, though individual families greatly vary in their coping strategies.

STUDIES RELATED TO MARITAL RELATIONSHIP:

Farber (1959) concluded that although marital satisfaction declined with the presence of a severely retarded child, outcome was more strongly related to the marital satisfaction of the parents prior to the child’s birth. Parents with high satisfaction early in the marriage seemed to do better than those whose satisfaction had been initially lower.

Rutter et al., (1970) stated that the presence of retarded child in the family brought about frequent quarrels between the parents. Srivastava et al., (1975) assessed the attitudes of mothers of mentally retarded children and found that the mothers fostered dependency in children. Marital conflict, strictness with children, easy irritation with children, suppression of aggression and avoidance of communication were some of the trends observed in families with retarded children.
Waisbem (1980) found no differences in marital satisfaction between two
groups of well matched couples, half of whom were parents of developmentally
delayed infants. Kazak and Marvin (1984) studied two larger groups, one of which was
composed of parents who had a child with spina bifida. The conflicting results of the
three studies may be attributable to sample differences as the children in the Friedrich
et al 1983, study averaged 9.8 years of age as opposed to 7.5 years in Kazak's study
and 13 months in the Waisbem's report.

The variability in the findings on marital satisfaction suggests that marital
response is not uniform and may be dependent upon factors other than the presence of a
retarded child. Such factors may be the severity of the handicap, the age and sex of the
child and the quality of the marital relationship prior to the presence of the child.

The implications of marital strife, social support, and the development of
mentally retarded toddlers were studied by Dashiff (1991). The birth of a mentally
retarded child is a stressful experience for the family. Research exploring the
differences between these families based on the child's developmental competence is
sparse. This study examined marital strife and social support within two groups of
retarded toddlers. The focus of marital agreement and disagreement differed between
the groups, as did social support. However, birth order and family life cycle stage were
found to be important confounding variables.

Mothers of 80 children of mild (IQ 50-70) and moderate (IQ 35-49) mental
retardation were selected for a study by Varma et al (1992). A carefully developed
home training programme was utilized to train half of the mothers, the other half
forming the control group for the study. The women also did not differ significantly on
base-line marital adjustment and parental attitude scores and the experienced social
burden of the mothers. In the experimental group there was a significant increase in the
IQ and improvement in the behaviour of the children and significant improvement in
the marital adjustment score, parental attitude and social burden felt by the mothers.

To investigate the long-term effects of a child's chronic illness or severe
physical or intellectual disability on parents and their marital relationship, the parents
of 89 children, aged 14-17, years were interviewed in a study by Taanila et al (1996)
One-fifth of the respondents had experienced the child's disability as contributing
positively to the marital relationship, 25% reported impairment in some areas of the marital relationship, while only 7% felt that they had drawn apart from each other. A higher level of occupational education, insecurity at onset, heavy daily demands for care of the child, unequal distribution of tasks between the spouses and a lack of time for leisure activities were found to be risk factors for impaired marital satisfaction. Adequate information, a realistic notion of the illness or disability and practical advice for everyday life seemed to be the protective factors for the marital relationship.

The study by Floyd et al (1998) evaluates how marriage and the parenting alliance affect parenting experiences over time. Couples (N = 79) with school-age children who have mental retardation completed self-report and observational measures of marriage, the parenting alliance, and parenting attitudes and behaviors. Significant effects of marital quality on changes over time in self-reports of perceived parenting competence for both the mothers and the fathers were observed. Parenting alliance mediated the effects of marriage on parenting experiences. There was little evidence of reciprocal causation in which parenting variables predicted change in the quality of marriage and the parenting alliance. Interactions involving child age suggested that teenagers as opposed to younger children were more reactive to negative features of their parents' marital functioning and parenting alliance.

STUDIES RELATED TO FAMILY INTERACTION AND FAMILY FUNCTIONING:

Family stress, family burden and coping styles adapted by families of mentally retarded children may directly or indirectly affect the functioning of the family. This may interfere with the individual’s adjustments as well as satisfaction which go a long way in raising a mentally handicapped child.

The overall meaning of the term “family functioning” is carrying out of family related roles. Poor family functioning indicates that relatively few of the tasks assigned to or expected of the family members are in fact being carried out. Family functioning is a dynamic concept relating to the way family members interact and carry out tasks. More specifically it is the process of fulfilling activities which contribute to the maintenance of the family unit and the well-being of its members.
The term family functioning has often been used interchangeably with family coping and family adaptation (Reiss et al., 1980) and family cohesion and adaptability (Olson, 1979). Family coping and family functioning may probably mutually affect each other.

Pelz et al., (1984) state that good family functioning can be indicated by individual member’s satisfaction with expressive activities.

Kershener (1970) compared family functioning in two groups of homes; in one group the mentally retarded child was kept at home while in the other child was institutionalized. The quality of family functioning was rated in a number of areas; home and household practices, economic practices, social activities, health and health practices, care and training of children, family relationships and family unity and individual behaviour and adjustment. As predicted, the level of functioning increased over the year interval for the families that institutionalized the child and decreased for those that kept the child at home.

Begab and Richardson (1975) observed that trauma of having a retarded child presents a serious disruptive force to the family lifestyle.

Pratt (1976) has described families who cope with stressful events as those who are characterised by flexible role relationship and shared power. Resources must be allocated among multiple goals to meet the needs of the family and satisfy relationships.

Browne G, Bramston P. (1996) reports on an investigation into quality of life in the families of young people with intellectual disabilities. Families with a member with an intellectual disability were found to have lower objective and subjective quality of life scores but were no different from the control group on the importance dimension. This finding implies that they have similar aspirations to other families but are unable to satisfy these aspirations.

Magill-Evans J et al (2001) compared adolescents with cerebral palsy (CP) and their families to adolescents without physical disabilities and their families as the child enters and leaves adolescence. There were few differences in family functioning, life
satisfaction, or perceived social support between the groups. Expectations of young adults with CP and parents of both adolescents and young adults regarding future independence and success were lower than the expectations of the control group. While the group results emphasize similarities between families during the two stages of adolescence, individual families and individual family members report specific challenges.

McCubbin et al., (1980) suggested that when it is the family unit rather than an individual who is dealing with a stressful event or problem the same resources are potentially available both to the individuals within the family and to the family as a group. The family system’s internal resources, namely, cohesion and adaptability need to be considered in this context.

Ishtiag and Kamal (1981) studied 20 moderately retarded children and their families. Results indicated that seventy two (72%) percent of the families had family disharmony as a result of birth of handicapped child. About 56 per cent of parents had a negative attitude, 88 per cent of the mentally retarded children were neglected by their parents.

Reiss (1981) in a series of experiments with over a thousand (1000) families found that families manage self-regulation within certain parameters and take on different aspects of one another’s functioning in order to protect the “balance” of the family as a whole.

Dybwad (1982) expressed that physicians, social workers and psychologists were convinced that the mere presence of a mentally handicapped child in a family would prove detrimental to other siblings and constitute an unbearable burden to the parents. The situation seems to be tense primarily because parents were left without services, without guidance and without emotional support of any kind.

Balachandran (1985) in an article on the role of family in the promotion of mental health of its members clearly emphasized the performance of some family functions server as support system to its members. The case study presented in the article reemphasized the potential that exists within a family unit that can be relied upon to restore and strengthen the individual.
Puri and Sen (1989) opined that the behaviour of mentally handicapped child was disruptive to the smooth functioning of any group whether in the family or in the play-ground or in the class room and could prevent the child's integration in such groups. The reaction of the group members to such disruption might be one of rejection, exclusion, punishment or the disorganisation of the group itself.

Dyson (1991) investigated the differences between families with children with special needs and those with children without special needs with regard to stress and family functioning. Fifty five (55) families with young children with handicaps were compared with a matched group of families of children without handicaps. Results indicated that parents of children with handicaps scored substantially higher on stress than parents of children without handicaps. The two groups did not differ on any domain of the family social environment. The results provided strong evidence that family stress is related to the care of a child with special needs, in middle class families.

The results further suggest that a child with handicaps may have differential effects on various family psychological dimensions and parental stress is not necessarily predictive of family dysfunction. This finding supports a competence model in which families may respond to the care of a child with handicaps with resilience and adaptive functioning. Special consideration needs to be given to identifying factors protecting families from the potentially negative impact of raising such children.

Waggoner K, Wilgosh L. (1990) studied the experiences and concerns of a group of parents of children with learning disabilities. Parents of eight different families were interviewed in depth, and seven themes emerged from the interviews. Parents discussed their involvement in their child's education, and their positive and negative experiences with school personnel as well as with seeking other sources of support. They expressed concerns about the social isolation and future well-being of their children with learning disabilities. They indicated many emotional strains from parenting children with learning disabilities and that there are both positive and negative effects on the families.

In a study by Sloper et al (1991) of families of children with Down's syndrome, measures of parent, family and child characteristics were obtained from mothers and
fathers. Personality factors were related to outcome for both parents. For mothers, the children's levels of behaviour problems, excitability and self-sufficiency were strongly related to outcome. Coping strategies, family relationships and socio-economic factors also showed significant effects. For fathers, child characteristics were not related to outcome. The marital relationship was an important factor and there was evidence that factors external to the family acted as stressors.

Cullen et al., (1992) investigated the variables influencing the functioning of families with mentally retarded persons. Sample consisted of 62 families with mentally retarded persons living at home in various stages of the life cycle. The implications of this study point to the need for greater support for mothers of young children with MR, mothers who are sole care-givers and parents with many children.

Rowitz (1992) has noted that “mental retardation is a family affair” and what is in the best interests of the family is generally in the best interests of the individual with developmental disabilities.

Stanton (1981) has emphasized that the family unit must be seen as people interacting with in a context, both affecting it and being affected by it. Consequently family focused interventions assure that family members can change and family paradigms may be modified thus allowing new behaviours and family patterns of functioning to emerge, if the overall family context is changed.

The purpose of the study by Van Riper et al (1992) was to examine the effects of a child with Down syndrome on the individual functioning of parents, marital functioning, and family functioning. Thirty-four families of children with Down syndrome were compared to 41 families with nondisabled children. Mothers and fathers in both groups completed a series of self-report measures. No significant differences were obtained between the two groups of families on any of the measures of individual, marital, or family functioning. The results of this study support a competence model in which parents may respond to the challenges associated with parenting a child with Down syndrome with resilience and adaptive functioning.

In a study by Perry et al (1992) mothers and fathers of 29 girls with Rett syndrome provided data about their levels of parenting stress, marital adjustment, and
family functioning. The parents of girls with Rett syndrome reported more stress, lower marital satisfaction, and certain adaptations in family functioning. There were few significant differences between mothers' and fathers' scores.

Another attempt was made by Nihira et al., (1994) who conducted home interviews with one hundred and two (102) families of children with developmental delays to assess ecocultural family resources and constraints, value and goals as well as pro-active adaptive efforts to deal with their circumstances. Interview topics included (a) economic factors, (b) child safety, (c) domestic and child care workloads, (d) familial support networks and (e) socio-cultural influences.

Results indicated that some of the eco-cultural factors were unique and statistically independent of the traditional measures of home environment (e.g. child-rearing attitudes, cognitive stimulation of the child and general psycho-social climate) significant relations were found between certain eco-cultural factors like (a) the family's attempt to seek information and services for the child with developmental delay, (b) the amount of help available in the family, and (c) the career and work orientation of the parents and child's developmental status. Both eco-cultural factors and traditional family measures accounted for significant variation in child outcomes.

The study by Snowdon et al (1994) was to examine relations between stress, coping resources, and satisfaction with family functioning in families caring for children with developmental disabilities at home. Fifty families who used the services of a respite care program were surveyed to examine relationships among child characteristics (behavioral problems and handicapping conditions); coping resources including mastery and health, esteem and communication, family hardiness, and social support; and the primary outcome variable of satisfaction with family functioning. Families of children with developmental disabilities experience significant stressors in terms of the severity of their child's handicapping conditions and behaviour problems. However, they reported satisfactory coping resources such as mastery and health, hardiness, and esteem and communication. Although they were lower than normative scores, social support scores for spouses and friends were related to satisfaction with family functioning.
A study by Rimmerman & Duvdevani (1996) examined out-of-home applications of 88 Israeli parents who had younger children and adolescents with severe mental retardation and, in particular, the question of whether parental application for placement is a function of their marital status, level of education, children's age, and parental stress, family environment (climate), social support, and attitudes toward normalization. Analysis showed that five predictors had significant correlations with parental application: parental stress (high), social support (less), attitudes toward normalization (favorable), family environment or climate (low), and children's age (adolescents).

Poston D, et al (2003) in this qualitative inquiry investigated the conceptualization of family quality of life. Focus groups and individual interviews were conducted with 187 individuals: family members (e.g., parents, siblings) of children with a disability, individuals with a disability, family of children without a disability, service providers, and administrators. Data were collected in urban and rural settings to elicit the participants' understanding of family quality of life. Ten domains of family quality of life were identified and described in terms of sub domains, indicators, and key points raised by participants.

In a study conducted by Holmbeck et al (2002) on the systemic functioning in families of preadolescents with spina bifida, it was found that compared to families of able-bodied children, families in the spina bifida sample were less cohesive and children from this sample were more passive during family interaction tasks.

The extent to which the families attempt to seek information and utilize services, the amount of help available within the family and away from family (internal / external resources) may have a direct / indirect bearing on parental marital relationship and parent child interactions.

The available literature on families of mentally retarded children suggested that the parents and siblings of retarded children individually as well as the family as a whole are at-risk for numerous difficulties in comparison to families with non-retarded children.
Studies of parent-retarded child interaction can be categorized as: (a) analysis of mother-child linguistic patterns and (b) studies of responsiveness and communications styles in mother-child interaction.

Mother's speech to their retarded children has received the most attention, with conflicting results. In the initial study Marshall et al., (1973) measured the frequency of verbal operands during interactions between 20 mothers and their retarded children and 20 mothers with their non-retarded children matched for CA. The non-retarded children used more and varied verbal operands and mothers of retarded children used more commands.

Several interaction studies measuring responsiveness and communication between groups of mothers with retarded and non-retarded children have yielded meaningful differences. Kogan et al., (1969) compared a group of 6 retarded children and their mothers with a control group of 10 mother non-retarded child pairs on parameters of relative status, affection and involvement. Mothers of retarded children displayed extreme degrees of warmth and friendliness less frequently. The retarded children generally displayed a more neutral status (neither dominant nor submissive).

Several subsequent investigators measuring interactive behaviour during free play and structured situations (Breiner and Forehand, 1982; Vitze, Abernathy Asha and Faultstich, 1978) have found a general synchrony in the interactive behaviour of mother-retarded child dyads. Mothers of retarded children tend to be more active and directive with their children. Retarded children were found to be both less responsive and less complaining to their mothers than were non-retarded children.

Floyd and Phillipe (1993) in a study compared the in-home interactions of mothers and fathers with their school age children with mild and moderate mental retardation (n = 53) and children without mental retardation (n = 51). The parents completed a battery of questionnaires that included the demographic variables like child adjustment, parenting attitudes, social support and psychological distress along with other measures of family relationships.

Researchers have begun to address the role of fathers of children with disabilities which often costs the father as peripheral to the child's development.
Tallman (1965) stated that the relative lack of involvement of fathers with their disabled children is due to their inability to cope with the situation. Gallagher, Beckman and Cross (1983) explained this as the father's discomfort with the female dominated service systems. Bristol, Gallagher and Schopler (1988) opined that because of role differentiation between parents, father's roles do not often include direct child care.

Some researchers have reported the father's role negatively. Fathers of children with disabilities are less likely to be playmates of their child than are fathers of children without disabilities. Bristol et al., (1988) McConachie (1982) and Parke (1988) have consistently shown that child care activities are not roles that fathers of children with disabilities ordinarily hold. Fathers spend less time in direct child care activities than mothers.

Ramadevi (1991) in a study regarding the attitudes of rural children towards their mentally handicapped siblings indicated that majority of children favored their retarded sisters to their retarded brothers.

The nature and severity of a handicapping condition are not the sole determinants of family functioning; the presence of a child with a pervasive developmental disorder has a significant effect on family members. Fisman & Wolf (1991) Maternal mental health suffers, and the resulting depression affects her role as mother and marriage partner. The impact on paternal psychological health is less, the fathers of autistic children are nevertheless highly stressed and appear to be particularly vulnerable to the stress generated by these difficult children. This finding is consistent irrespective of the sex, age, ordinal position and educational level of siblings of retarded children.

The results of the study by Andersson (1997) on relations in families with a mentally retarded child from the perspective of the siblings indicate that siblings of mentally retarded children seem to adapt to change in the family because of the mentally retarded child and qualitatively alter their thinking in relation to the family members.
Horiguchi et al (1999) assessed the status of mental health of families caring for relatives with developmental disabilities and neurological diseases. They were caring for their children in good morale; however, "burnouts" or neurotic conditions were more frequent in these families. Mentally healthy persons consulted their spouse about their children as well as other things, and received his/her assistance in daily care. Families helped by unrelated persons were in better mental state. Families who had utilized inpatient care before entering a school had higher expectations from their surroundings. Therefore, medical services should provide support to such families to help improve their mental health.

Witt W.P et al (2003) examined the associations between children's functional status, family stressors, and the psychosocial adjustment of school-aged children with disabilities. Results indicated that child's functional impairments in the areas of communication or learning; poor maternal health and mental health, family burden, and poverty were significantly and positively associated with psychosocial maladjustment among children with disabilities.

STUDIES RELATED TO SOCIAL SUPPORT:

Families in general are embedded in a set of informal and formal support systems can significantly modify the interaction of family members and thereby often affect the developing child. A number of studies have suggested that there is a positive relationship between informal social networks and a family's adaptation to stressful events, such as divorce and jobloss. In the case of families with retarded children social networks are particularly important to successful coping and adaptation.

Research has indicated that factors that act as inhibitors to effective coping vary over the life cycle (Suelze & Keenan, 1981). Research by Suelze & Keenan (1981) has indicated the following as important inhibitors to effective coping: additional financial hardships, stigma, extraordinary demands on time, difficulties in caregiver tasks like feeding, diminished time for sleeping, social isolation, less time for recreational pursuits and difficulties in managing behavior problems. Research in India has indicated that inability to perform routine social and household work satisfactorily in the family, interpersonal conflicts either between parents and other children, additional
responsibilities, marital disharmony and social isolation were major inhibitors to effective coping (Moudgil, Kumar & Sharma, 1985; Jain & Sathyavathi, 1969).

Families of handicapped children often have smaller informal networks and hence report more social isolation (Kazak, 1987). In addition, other factors reported to act as facilitators in coping include parents having better physical health (Turnbull & Turnbull, 1990); family characteristics like high degree of cohesion and expressiveness; and the presence of active reaction in the family (Bristol, 1984); Mink, Nihira, & Myers, 1983).

Davis (1967) reported that the maternal grandmother usually plays an important role in the life of the new family. Fifty families with retarded children were compared with 30 normal families in order to determine the support given by the maternal grandmother. Support is described as “intimate” if the maternal grandmother lives nearby and visits frequently; as “effective” when she is available on call; as “ineffective” when there is little or no contact and as “unfamiliar” when she is not available. Less than one-half of the families with a retarded child had “effective” support from the maternal grandmother. In contrast, the normal control families received “effective” support, three quarters or more of the time. The reason given for this finding probably lies in the quality of family’s relationships which tended to be strained in those with a retarded child, rather than in geographical factors. In order to find out exact pattern of support and relationships, it may be necessary to focus the attention on the available support system models.

Caplan (1976) suggested a model of support systems which focus on the health promoting and ego fortifying effects of social aggregates. He observes that an individual’s continuing interaction with another individual or group or organization can add to his abilities of coping with his environment. The special attributes of such support systems lie in their acting as a “buffer against disease” by providing the individual with feedback about his environment, by being interested in him as a person and by respecting his unique needs.

However, there are studies which conclude support systems do not influence the extent of stress experienced by mothers of retarded children. One such study is reported below.
Bradshaw and Lawton (1978) assessed the relation of mother’s level of stress to the social and economical circumstances of the family. It was concluded that little of the variation in the level of stress could be ascribed to the extent of social and physical conditions of the family and child and that the provision of goods, services or financial assistance did not appear to have an impact on the level of mental well being of the mothers. Thus the overall conclusion of the study was that neither the severity of the handicap not tangible support service and external environmental conditions were significantly related to maternal stress associated with caring for a handicapped child.

But, Johnson and Sarason (1978) have reported that social support has a demonstrated buffering effect. High stress families with high social support cope better than do similarly stressed families with low social support and low stress families do equally well with or without peer social support. The relationship is interactive in that better copers presumably have more social support and more social support facilitates coping.

Friedrich (1979) found that social support was not significantly related to coping.

Silver and Wortman (1980) identified the presence of social support as one of the important variables influencing the individual’s coping process. In the case of social support actual social support is less important than perceived social support because an individual may under-estimate or over-estimate support resources. Also the simple presence of social support is not helpful if the individual is unable or unwilling to use it.

Waisbem (1980) in a study comparing Danish and U.S. parents of disabled children found that the relationship between use of support systems and coping was a complicated one. Support from informal sources such as family was found to be related to positive feelings towards the child. Still the families experienced more symptoms of internal stress. Format support services such as help from professionals or social agencies were not found to figure prominently in lessening the internal strain or facilitating positive adjustment to the birth of a developmentally disabled child.
Wahler (1980) reported that mothers who did not profit from a parent training approach were characterized by insecurity that is they lived within sparsely constructed community social networks. These mothers differed in the functional nature of their social contacts as well. The type of support offered to these mothers tended to be directive and instructive, which was apt to be punishing to the insular mother.

Suelzle & Keenan (1981) studied the family support networks over the life cycle of mentally retarded persons. Utilization of personal and professional support networks by parents varies over the life cycle of their mentally retarded children. Parents of younger children utilized more services and support networks and were more supportive of mainstreaming; parents of older children were less supported, more isolated, and more in need of expanded services.

Tucker (1982) reviewed literature indicating that it is the absence of support that interferes with adjustment and not the presence of support that facilitates it. German et al., (1982) studied social support and coping in families with a mentally retarded child maintained at home. Support and help received from grandparents and extended family members was perceived as more valuable than from friends.

Beckman (1983) observed that friendship networks were significantly smaller for parents of mentally retarded children when compared with parents of normal children. However, family network sizes were equivalent and were more closely knit among parents of retarded children.

Kazak and Marvin’s (1984) study reported that though the family support system fostered cohesiveness and support, it also generated stress as the avenues to other resources are limited.

The purpose of the study conducted by Brandt (1984) was to obtain an understanding of social support and its relationship to negative life events experienced by mothers of developmentally delayed children. The findings of this study indicated that the mothers with a high impact of negative events over the past year felt less supported as measured by perceived support and felt less average satisfaction with the help obtained during problems. The relationship between negative life events was maintained whether negative life events were measured subjectively (impact) or
objectively (number). Thus, the more struggles these mothers had, the less they felt supported.

The mediating influences of social support were examined in a study (Dunst et al. 1986) of 137 parents of mentally retarded, physically impaired, and developmentally at-risk children. Social system theory was used as a conceptual framework for assessing the effects of social support on personal well-being, parental attitudes toward their child, family integrity, parental perceptions of child functioning, parent-child play opportunities, and child behavior and development. More supportive social networks were associated with better personal well-being, more positive attitudes, and more positive influences on parent-child play opportunities and child behavior and development.

Predictors of four indices of well-being among 203 aging mothers of mentally retarded adults who live at home were examined by Seltzer & Krauss (1989). Maternal demographic variables (age, marital status, education, and income) correlated with maternal physical health and life satisfaction, whereas adult child risk factors (level of retardation, having Down syndrome, physical health, and functional skills) related more strongly to parenting stress and burden. The family's social climate was a better predictor of maternal well-being than were formal or informal support.

In a study conducted by Erickson & Upshur (1989) data concerning mothers' perceptions of child caretaking burden, fathers' participation in child caretaking, and satisfaction with social support were analyzed for a 202 member sample consisting of mothers of infants with Down syndrome, motor impairment, developmental delay. Significant differences among the four groups were found on difficulty of and time devoted to caretaking, number of tasks with which fathers helped, and satisfaction with support from family, friends, and community groups.

Haldy et al. (1990) concluded that adequate social support had a positive influence on maternal feelings of competence about their child rearing abilities. Maternal satisfaction with help received by family members in caring for their child was positively correlated with feelings of competence. Mothers reported greater satisfaction with advice and services from various professionals when their child fell in milder mental retardation group.
Baker et al., (1991) studied the effects of parent training on families of children with mental retardation. Forty nine (49) families of children with mental retardation were assessed before and after a parent training programme on a variety of parent, marital and family measures. Parents reported high satisfaction with the programme and showed small but statistically significant decreases in reports of symptoms of depression, parent and family problems, overall family stress and dissatisfaction with the family's adaptability. The families that reported doing the least productive teaching had entered training reporting greater child related stress and lower satisfaction with the marriage and the family. The results suggested that the eventual success of parent training might be enhanced if programmes also intervene to enhance marital satisfaction or increase family adaptability or decrease stress-areas that are predictive of poorer long-term outcome.

Beckman (1991) reported that for both mothers and fathers of children with disabilities, increased informal support was significantly associated with decreased stress. Unlike informal support, formal support was not significantly associated with lower levels of stress. However, for fathers formal support was significantly negatively associated with general life stress.

An evaluation study of a home-based, family-focused counseling scheme providing support for English-speaking and Bangladeshi families of children with intellectual or multiple disabilities was conducted by Davis & Rushton (1991). Mothers and children in the intervention groups showed significant and positive changes compared to randomly allocated controls. Mothers changed positively in ratings of perceived support and family functioning.

Karp & Bradley (1991) speak of the gradually developing programs in the United States to support families with special needs. Some offer exemplary models and others offer virtually nothing to support families. Value-based, family-centered, accessible, equitable family support programs are greatly needed. This will send a message to people with disabilities and their families that we value them, care about them, and want them to be part of their communities. In the words of some family support program participants: "Even though our daughter has multiple handicaps, our desire is to care for her at home, in a loving environment that all children should have
the opportunity to experience. "It allows us to keep our daughter at home and file the possibility of putting her in an institution

Religious and nonreligious families were similar on other measures of developmental beliefs and social support. Religious parents described the "purpose" of their children with delays in their lives in emotionally powerful and meaningful ways that clearly helped them, although direct measures of peace of mind and emotional adjustment did not differ between religious and nonreligious families. Weisner et al (1991).

Flynt et al., (1992) examined the perceived stress and the type and extent of social support utilized by mothers of children with mental retardation across the life cycle. Subjects were eighty (80) mothers of children who were developmentally delayed or diagnosed with moderate mental retardation. The children ranged in age from 6 months to 20 years. Results indicate that there were no significant differences in stress scores across the age groups. The perceptions of stress were stable for mothers of pre-schoolers through young adults. Significant differences were observed initially on utilization of social support by the mothers of pre-schoolers. However, when marital status was co-varied differences between groups were no longer significant. An analysis of the subscales of the questionnaire on social support showed that a significant difference existed between intimate relationships, friendships and community or neighborhood supports for the mothers of preschoolers. An emerging trend suggests that mothers of preschoolers’ utilized social support to a greater extent than did mothers in the other two groups and these mothers relied more on intimate support than either friendship or community support networks.

A number of models were advocated as support systems to the parents of mentally handicapped.

Peshawaria and Menon (1992) were optimistic in saying that parents and families are no doubt the biggest strength in India at present, though there are difficulties encountered while working with the families of children with mental handicap. Among the difficulties observed are financial burdens with no support from anywhere, large size of the families, misconceptions in parents regarding the condition
of mental handicap, parental reliance on magical medical cures, and transportation
problems in reaching available services.

Another problem parent’s face in our cultural set up, where guests are welcome
anytime at home the parents are not able to carry out the programme at home due to
this extra burden. Sometimes the over involvement and interference of neighbors and
relatives, who suggest to parents methods of managing the child with mental handicap
with other than systematic training leaves parents very confused.

The problem of both parents working with no extra support at home is posing a
major college for parents of children with mental handicap and the service providers.
Nevertheless, the strength of parents cannot be ignored and the fact that parents in India
live and work for their children cannot be forgotten.

Girimaji (1993) overviewed the family intervention in mental retardation and
stated that home-based family care approach in mental retardation has gained
worldwide recognition and research attention especially in the last two decades. He
further states that there are clear advantages to the individual with mental retardation as
well as to society in promoting family based care. However, there is a need to work
with families to ensure optimum care as well as successful family adaptation.
Approaches to such family interventions include; (a) parent education, (b) parent
training, (c) parent counselling, (d) family social support networking and self-help
groups and (e) transactional intervention.

Girimaji lays stress on the study of parents with an emphasis on parent’s needs,
parent’s perception and attitudes. A small but significant body of research work has
emerged reporting different forms of family intervention. Brief inpatient family
intervention model developed at NIMHANS in 1985 is worth mentioning in this
context. This model could be considered a great support to parents of children with
mental handicap. The model has been evolved to meet the needs of sub-groups of
families who needed intensive intervention for reasons such as presence of high degree
of stress and/or poor coping skills in the family following the birth of mentally
handicapped child. However, the model seems to offer comprehensive care as it has
been tailored to suit the needs of individual child and family.
According to Folden & Coffman (1993) the number of children with chronic health problems and resultant disabilities is increasing. Most of the care received by these children is provided by family members, often at severe economic and psychological cost. One service that has appeared in the past two decades to assist family caregivers is respite services.

McConachie (1994) explored the coping strategies adopted by families bringing up a disabled child to deal with stress. They emphasized the importance of social support networks, including the relationship between the mother and father, and of quality services in enhancing parental adaptation.

Sandlers et al (1995) studied the source of emotional support for parents of children with disabilities. Measures of emotional adjustment and perceived emotional and instrumental support by grandparents were administered to parents of young children with developmental disabilities. A significant positive correlation between paternal adjustment and grandparent support was found. Grandparents' most frequent forms of assistance were babysitting and buying clothing. The results supported the importance of grandparents as a source of support to families with a child who has a disability.

Working with children who have mental retardation and their families is challenging and rewarding according to Lubetsky et al (1995) When these children also have behavioral/psychiatric problems, the challenge is far greater. An interdisciplinary team is needed for comprehensive assessment, treatment, and management in order to be successful in accomplishing goals, providing continuity of care, and supporting the family in the community.


Moore G, et al (2003) studied the role of the school nurse in special schools for pupils with severe learning difficulties. The presence of the nurses in schools was valued by school staff, parents and other health and social care professionals thus serving as a very good form of social support.
Johnson BS. (2000) studied mothers' perceptions of parenting children with disabilities. The purpose of this study was to describe how mothers of children with physical disabilities identified their parenting strengths and weaknesses, encouraged their child's social skills and learning, nurtured and disciplined their child, and perceived their parenting successes and problems. Results indicated that parents were living in the past and the present, striving to view their child as "normal" when, in fact, the child was disabled, and were simultaneously dealing with their own and their child's issues and feelings. The researchers felt that nurses need to understand the complexity of the parents' straddling their roles and tasks. They can provide needed emotional support by allowing parents to express their fears and feelings in an atmosphere of nonjudgmental acceptance. Nurses can prepare parents for anticipated grief work, reassure them that their experiences are expected and normal, reinforce their use of normalization strategies, and help them separate their own from their child's issues and feelings.

The study by Hodapp et al (1997) examined stress-support in 42 families of 3 to 18-year-old children with Prader-Willi syndrome. Parents were asked about themselves and their families, their child with Prader-Willi syndrome, family supports, and family stress. Compared to 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 children with Prader-Willi syndrome listed other family members and friends as their main supporters. Families experienced greater stress when the child showed more behavior problems.

To meet the needs of individuals with mental retardation and developmental disabilities (MR/DD) and their families living in urban setting, a noncenter-based model of case management was implemented by Ardito et al (1997). It was found through this study that to build and maintain an egalitarian and supportive relationship with families, the importance of caregiver-specified resources and needs must be recognized by case managers. Access to resource information and the ability to engage the family in problem-solving depends on a well-trained staff with the ability to respond to individuals with different needs and from a variety of circumstances.
The study by Hoare et al (1998) describes a cross-sectional study of the psychosocial adjustment of 143 children with severe disability and their families. Distress among carers was consistently associated with increased disability in the child. Although respite care is a valuable resource for many carers, its use is indicative of underlying distress in the carer.

Oka & Ueda (1998) study focuses on overt and covert problems experienced by mothers with disabled pre-school children and the resources that are available for coping with them. The results of the indicated the following: 1) The major source of strength for the mothers with disabled children was the availability of a social support network, which consisted mainly of their own mothers and grandmothers, 2) The mothers with disabled children had insufficient time and little respite for themselves, and 3) Emotional support from mothers who shared the same experiences was effective for coping with problems associated with the acceptance of disabled children. The support of health care professionals, however, had little effect in helping the mothers who were under stress, though they could help to change such mothers' attitudes. There was a possibility to facilitate mothers' coping skills if mothers with disabled children could get effective support at appropriate times. These results support the concept of empowerment.

200 Latino parents (50 Mexican couples, 50 Puerto Rican couples) living in the United States were studied by Bailey et al (1999) to determine needs and supports related to raising a child with a disability and to identify variables related to reported needs and supports. More support was reported from family and formal sources than from friends or informal sources.

The role of familism (a cultural value including interdependence among nuclear and extended family members for support, loyalty, and solidarity) in caregiving was explored for Puerto Rican mothers with children with mental retardation living at home by Magana (1999). Familism—defined here as direct caregiving provided by family members to the person with mental retardation, mothers' social support networks, and mothers' obligations to other family members—was hypothesized to account for variation in maternal well-being. Better maternal well-being was predicted by larger social support networks, greater satisfaction with social support, and more minor
children living in the household. These mothers faced many socioeconomic challenges and were in poor health in addition to the challenges of parenting a child with mental retardation.

The study by Pelchat et al (1999) assesses the effects of early intervention programmes. The results show a better adaptation among parents who participated in the intervention programme compared to those who did not participated in the programme. These parents had lower levels of parental stress, they had more positive perceptions and attitudes concerning their child's disability and their parental situation, they were more confident in their own resources and the help they could receive from others, they had lower levels of emotional distress, anxiety and depression and they perceived more emotional support from their spouse.

The purpose of the study by Van Riper (1999) was twofold: (a) to describe parental perceptions of family-provider relationships, and (b) to explore links between parental perceptions of family-provider relationships and well-being in families with children who have Down syndrome. The results indicate that when mothers of children with Down syndrome believe that their family's relationship with health care providers is positive and family-centered, they feel more satisfied with the care that their child is receiving and they are more likely to seek help from health care providers. In addition, when a discrepancy exists between what mothers want the family-provider relationship to be and what they believe the relationship is, mothers feel less satisfied with the care that their child is receiving. Finally, higher levels of individual and family well-being are reported by mothers who (a) want, and believe they have, positive family-centered relationships with providers, and (b) feel more satisfied with care received.

Ellis & Hirsch (2000) studied the reasons for living in parents of developmentally delayed children and found that when children are diagnosed with developmental delays, their parents may experience psychological turmoil similar to that experienced by suicidal individuals. Adaptive characteristics that may or may not be present in parents of children with developmental delays were also studied. The experience of having a disabled child may help to strengthen adaptive characteristics and, possibly, reduce the risk of suicide.
Gerry & Bodil (2000) compared how adults with developmental disabilities perceive quality of the care and service they receive and compared with those of their parents and primary caregivers. Results showed it was possible to assess how adults with developmental disabilities evaluated actual care and service conditions. A high degree of similarity was found in ratings of perceived reality of care and service conditions by the adults with developmental disabilities, their parents, and caregivers.

A study on the importance of empowerment of people with developmental disabilities was done by Ogawa (2000). Social isolation of the disabled people and their families, lack of resources, and discrimination have resulted in their disempowerment. The study also discusses the professionals' role in empowerment of the families.

Shimizu (2000) describes three social movements by families with a disabled child: (1) respite services which refresh family members by a short-term relief care in a local region, (2) after-school activities in which children with disabilities participate in recreation activities and built up a friendship with non-disabled people in neighborhood, and (3) schooling of children with special health care which enables the children to attend unaccompanied by mothers until after-school hours.

The authors Horiguchi T, Uno A. (2000) surveyed handicaps in daily life of persons with learning disability (LD) or its related conditions. Among 470 parents of persons with LD, 266 (56.6%) responded. The required assistance differed according to the age and handicaps. Whereas 18.0% of the respondents were utilizing current social services, 75.3% agreed on the establishment of special welfare for LD. Social supports, comprehending medicine, education, occupation, and law are needed.

Hoashi (2000) study on early diagnosis and early intervention for mentally handicapped children says, to support a mentally handicapped child and his/her family, it is very important to understand problems concerning the first-step of life-long help: early detection, intervention and treatment of the child in infancy or toddlers.

Barnhart (2001) reviews the literature about families of adult children with developmental disabilities, the impact of culture on access to health care services, and community-based health care services for adults with developmental. Therapists need to use approaches that will empower children and their families so they can better meet
their current challenges and provide a foundation for the skills they will need to meet future challenges as adults.

The purpose of the study by Rimmerman & Muraver (2001) was to examine the extent to which 160 mothers 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 of age peers. Findings indicated that caregivers for adult children with mental retardation reported more undesired daily life events in comparison to the matched group. However, no differences were found in respect to their instrumental functioning, social support and well-being.

Van Wouwe et al (2001) stress the importance of optimal medical care for children with Down syndrome and their parents. Children with Down's syndrome have an increased risk of congenital anomalies and additional medical problems. A well-balanced disclosure of the diagnosis, repeated medical screening, early motor training and social interventions combined with active parental participation, warrant optimal development which could serve as a source of support.

Physicians can provide the necessary support to parents of intellectually disabled children. Ryan et al (2001) stress the physician's unwitting participation in abuse and neglect of persons with developmental disabilities. The vast majority of birth parents and foster parents for children with special needs do the best they can in challenging circumstances. Many describe the frustrating circumstance of knowing more than their physicians about their child's unusual medical conditions. Physicians are therefore well-advised to listen carefully to the reports of observant, caring parents and foster parents, and to give these observations at least as much weight as their own.

Rhoades Smucker JM. (2001) studied the special challenges for providers and parents alike in providing care to children with special health care needs within a managed care environment. To provide comprehensive, coordinated, family-centered care, the medical home provider must learn about a variety of services available within the community and guide parents in learning how to access the services that meet their child's needs. Pediatric nurse practitioners can play a significant role in ensuring that children receive the most appropriate care.
Provision of respite care is seen as an important means of alleviating individual carer stress. The authors (Hartrey L and Wells JS.2003) found that mothers, whilst some of the predicted benefits of respite care were present, for example improved social activity, their use of respite care and the experience of separation initiated feelings of guilt and appeared to engender a degree of emotional stress.

Cowen & Reed (2002) stressed that respite child care programs that provide temporary child care, support, and referral services to families of children with developmental disabilities are thought to be a critical component of formal social support interventions deemed it necessary to promote healthy family functioning and prevent child maltreatment.

Parental perceptions of eight physical and human resources available to meet the needs of children with developmental disabilities in Kenya were studied by Mutua et al (2002). The study assessed the discrepancy between the importance parents attached to specified resources and the expected use of those resources by their children with developmental disabilities. Discrepancy analysis was conducted on parents' expectation-to-importance appraisals of eight resources - health, education, friendships, husband/wife, religious organization, community membership/acceptance, employment/work, and home. Most parents reported a match between expected use and importance in five of the eight community resources.

A study by Weiss (2002) assessed the effects of social support and hardiness on the level of stress in mothers of typical children and children with developmental disabilities. One hundred and twenty mothers participated (40 mothers of children with autism, 40 mothers of children with mental retardation, and 40 mothers of typically developing children). Results indicated significant group differences in ratings of depression, anxiety, somatic complaints and burnout. Regression analyses were conducted to determine the best predictors of the dependent measures. Both hardiness and social support were predictive of successful adaptation.

Einam & Cuskelly (2002) speak about paid employment which is increasingly undertaken by mothers as their children age, with the majority of women being in employment by the time their offspring are adult. Opportunities to engage in employment appear to be reduced for mothers of children with disabilities. Increased
attention needs to be given to the employment opportunities of parents of children with disabilities since employment appears to play a protective role for mothers, in particular.

The aims of the study by Shu et al (2002) were to describe the change in mental health over time in a group of family caregivers with a child with intellectual disability (ID) and to explore the effect of a home care service on the psychological well-being of the caregiver. The findings of this study accredit the effect of home care services and suggest that home care services are necessary for family caregivers.

Thyen et al (2003) sought to determine the independent effect of unmet health needs on family burden, in addition to the effects of functional impairment and parental care load, in children and adolescents with disabilities. It was found that lack of medical services, contributed significantly to family burden. Addressing unmet health needs may alleviate the impact of caring for a child with a disability.

The studies thus far reviewed give a clear indication of the impact that a child with mental retardation can have on the various dynamics of the family. The vivid picture emerging is that stress is the predominant force at work with such families having its impinging effect on the other family functions.