CHAPTER II

REVIEW OF RELATED LITERATURE

Research in any field, is a step ahead in the exploration of the unknown concepts and an investigator should be well prepared to take this step. Review of the related literature is an important pre requisite to actual planning and then the execution of the research work. The review of the related literature allows the researcher to acquaint with current knowledge in the field of her interest. Besides this, it enables the researcher to define and delimit her problem. It also gives the researcher an understanding of the research methodology, methods used for data collection, information about various tools, techniques of analysis of results etc. and helps to be systematic in her endeavour of investigation. The study of related studies works as a guiding part to perceive the gap in the concerned field of research. A familiarity with the literature in any problem area helps the researcher to discover what others have attempted to find out, what methods have been promising and disappointing and what problems remain to be solved. The review of the past research also helps a researcher to avoid duplication of the work already done in that area.

Though it was not possible for investigator to get access to the entire literature in the related field, yet an attempt was made to collect some information about the studies already conducted in the field relating to the present problem. The relevant results of studies have been briefly presented to provide the background material so as to evaluate the significance of this study as well as to interpret its findings. The results of various reviews of related literature have been presented briefly under the following headings.

2.1 Review of the literature related to intellectually disabled children and their behaviour problems

2.2 Review of the literature related to mothers of intellectually disabled children and their selected psychological variables
2.3. Review of the literature related to mothers’ coping with intellectual disability of their children

2.4 Review of the literature related to guidance to mothers for coping with intellectual disability and its implication on behaviour problems of their intellectually disabled children

2.1 REVIEW OF LITERATURE RELATED TO INTELLECTUALLY DISABLED CHILDREN AND THEIR BEHAVIOURAL PROBLEMS

Reviews related to intellectually disabled children and their behavioural problems are presented below

Koller, Richardson, Katz and McLaren (1982) conducted study on prevalence rate of psychopathology in children with intellectual disability, the results of the study revealed that prevalence rate of psychopathology in children with intellectual disability was about seven times higher than in the non-intellectual disability of comparison group.

Koller, Richardson and Katz (1983) indicated that the highest rate of behaviour disturbance in children with mental retardation occurred in families in clusters where rates of psychiatric disturbances were higher for mothers.

Matson and Smith (1986) observed that age and level of mental retardation proved to be significant factors in predicting treatment outcome. Also, it was found that some types of behaviours were treated more frequently than others, with inappropriate verbal responses being the most common, followed by noncompliance and aggression toward others.

Quine (1986) found that there was a significant association between behaviour disorder and incontinence, lack of self-help skills, poor reading, writing and counting skills, and poor communication skills of mentally retarded. Environmental correlates were few. There were no differences between groups in family size, birth order, age of parents, marital discord, social class or income. However, behaviour problems were more common in one-parent families. An association was also found between maternal stress and problem behaviour.
Dadds (1987) studied relationship between child behaviour and family variables and concluded that moment to moment interaction between child and his primary caregivers was important for the proper development and maintenance of conduct disorders in children.

Margalit, Shulman and Stuchiner (1989) investigated feelings of stress among parents of mentally retarded children who demonstrated behaviour disorders and found significant differences between the children's levels of pathology validated the two groups' division. The children with disruptive behaviour were described by their parents as more hyperactive and aggressive, and were described by their teachers as more distractable and dependent on adults. However, levels of children's pathology and aspects of family climate predicted the parental stress, pinpointing different patterns of variables for fathers and mothers.

Orr, Cameron and Day (1991) emphasized that children having developmental delay were strong sources of emotional distress for their mothers. The middle childhood group having developmental delay reported a significantly greater frequency of behaviour problems than the adolescent group having developmental delay. The results also revealed that the behaviour problems appear to be a strong predictor of emotional distress for mothers of disabled individuals of both the groups.

Kagan (1992) found no definite relationship between the type of difficult, harsh and uncongenial environment and type of behaviour problems. He emphasized that generally, it was the interaction of multitude of factors which lead to behaviour problems in the children. The factors such as gender and age of the children played an important role in determination of the type of behaviour problems. He also pointed that the girls are generally found to suffer more from anxiety, depression and withdrawal behaviour problems, whereas, the boys suffered from aggressive behaviour and conduct problems.

Parcel and Menaghan (1993) observed that those mothers who had mastery in handling the complex situations, possessed positive attitude and provided
conducive home environment, successfully protected their children against behaviour problems.

Charlton and Leo (1994) studied the rate of prevalence of behaviour problems in mentally retarded children and found that the prevalence rates of behaviour problems in mentally retarded children was 6.9% as assessed by Rutter's Behaviour Questionnaire, which was among the lowest found by the investigators.

Ramgopal and Rao (1994) studied the behaviour disorders in moderately mentally retarded and their relationship with parental attitude. The finding showed that anxiety and aggressive behaviour problem were the highest among the mentally retarded children and these problems decreased with positive parental attitude.

Campbell (1995) indicated that serious externalizing behaviour problems persisted with negative and inconsistent parental behaviour. High levels of family adversity were associated with the emergence of problems in early childhood.

Kuczynski and Grazyna (1995) studied the developmental significance of early demands for competent action. Results of the study revealed that the maternal demands for competent action led to enhanced compliance and fewer behaviour problems at the age of 5 years. Also, the demands focused on the regulation of personal and social behaviour predicted more behaviour problems at the age of 5 years.

Peshawaria, Venkatesan and Menon (1995) analyzed the areas of behaviour problem in the mentally handicapped persons and found that the parents predominantly seek help for managing behaviour problems of disobedience (15.8%) in their mentally handicapped children and the least perceived behaviour problem was sexual area (0.9%).

Rothbaum, Rosen, Pott and Beatty (1995) found that attachment to mother predicted low total behaviour problems score at home and maternal
acceptance predicted low total behaviour problems score both at home and school.

Benasich and Jeanne (1996) found that the maternal knowledge and quality home environment effected child's cognitive and behavioural outcomes.

Feldman, Hancock, Rielly, Minnes and Cairns (2000) examined the prevalence of behaviour problems and their relationship to child, parent, and family factors in children with or at risk for developmental delay. Parents reported that 42% of the children had behaviour problems. They revealed that 25% of the sample scored above the borderline cutoff and increased total scores were significantly related to dependency and management of the child, birth weight, gestational length, paternal illness, maternal depression, perceived personal burden of care, maternal escape-avoidance coping strategy, family disharmony, and financial stress. Also behaviour problems were significantly negatively correlated with paternal education, maternal employment, two-parent family, family social support, and family income.

Baker, Blacher, Crnic, and Edelbrock (2002) studied the behaviour problems and parenting stress in families having children with and without developmental delays. They found that children and adolescents with mental retardation were at heightened risk for mental disorder. They examined early evidence of behaviour problems in three-year-old children with or without developmental delays and the relative impact of cognitive delays and problem behaviours on their parents. Results showed greater problems in children with delays than in those without delays. Children with delays were 3 to 4 times as likely to have behaviour problems within the clinical range. Parenting stress was higher in delayed condition families. Regression analyses revealed that the extent of child behaviour problems was a much stronger contributor to parenting stress than was the child's cognitive delay.

Juyal (2002) found that the attitude of the parents of mentally handicapped children differed in respect of acceptance, permissive and domination of their children. Mentally handicapped children also showed better emotional
adjustment at home when accepted by their parents and had lesser behaviour problems.

Mehta (2002) revealed that non-contingent reinforcement was effective in suppressive behaviour problems and use of positive reinforcement and establishing positive links with mentally challenged subjects helped in bringing a positive change in their behaviour.

Baker, McIntyre and Blacher (2003) found that behaviour problems were both predictive of and predicted by parents’ stress, indicating that the higher instance of behaviour problems in children with developmental delays are functionally related to early family stress and subsequently associated with higher levels of family stress at later periods.

Campbell and Richard (2003) found a wide variety of disorders in mentally retarded including schizophrenia, depression and conduct disorder. It was found that specific disorders were related to the level of retardation, and the treatment given included educational, behavioural and pharmacological interventions but guidelines for safe use of psychotherapeutic drugs were also emphasized.

Gray (2003) found that the adjustments to the reality of the child’s condition, housing and finance were the factors that influenced parental stress. Also, in the families having aggressive or violent children, the parents experienced high levels of stress and had few resources in terms of treatment or residential placement to deal with their situation. Mothers and fathers also coped differently with emotional distress, with fathers typically suppressed their feelings, often at the cost of anger.

Kishore, Nizamie, Nizamie and Jahan (2004) examined the rate of psychiatric diagnosis as per ICD-10 and Reiss Screen for Maladaptive Behaviours and distribution of psychiatric diagnosis with regard to the severity of intellectual disability. The results of the study concluded that the persons with intellectual disability suffer from various psychiatric disorders. Commonest psychiatric diagnosis was unspecified psychosis followed by bipolar affective disorders.
Mukherjee, Kaushik, Mukherjee and Kumar (2007) pointed that people with disabilities were excluded from main-stream of society and faced a number of barriers due to their behaviour problems. Reassurance provided through peer support groups helped the disabled persons to learn from each other.

Phetrasuwan and Miles (2009) observed that behavioural symptoms were the primary source of parenting stress for mothers. There was no relationship between child characteristics and parenting stress. Mothers reported more parenting stress had more depressive symptoms and lower levels of well-being. Results of the study had implications for interventions with mothers to help them manage their children's behaviour and focus on stress reduction and well-being.

Nestler and Goldbeck (2011) found that problems of emotional and behavioural problems and lack of social competence were common in adolescents with borderline intellectual functioning and impaired their social and vocational integration. Group interventions specifically developed for this target group were scarce and controlled evaluation studies were absent. They developed cognitive-behavioural group training and examined its effectiveness. Effects of the intervention on other outcomes such as problem-solving competence and skills performed in standardised role plays were weak or absent. It was concluded that social competence training for adolescents with borderline intelligence was a promising treatment for adolescents with borderline intellectual functioning and associated emotional/behavioural symptoms.

Neece, Green and Baker (2012) pointed that parenting stress and child behaviour problems have been posited to have a transactional effect on each other across development. The authors investigated the relationship between parenting stress and child behaviour problems from ages 3 to 9 years old among 237 children, 144 of whom were typically developing and 93 who were identified as developmentally delayed. Behaviour problems and parenting stress covaried significantly across time for both groups of children. Cross-lagged panel analyses supported a bidirectional relationship between parenting stress and child behaviour problems for mothers and fathers.
Taylor and Hodapp (2012) observed that parents and professionals were concerned about the fact that individuals with intellectual and developmental disabilities go without regular educational and vocational activities. Results revealed that nearly 13% of individuals with intellectual and developmental disabilities were without daytime activities; these individuals had more emotional–behavioural and health problems, were more underserved by the formal service system, and had parents who were less able to provide care. Although siblings of individuals without activities reported more depressive symptoms, worse health, and less close sibling relationships, inactivity no longer predicted these problems after controlling for characteristics that predisposed individuals with intellectual and developmental disabilities to have no activities.

It was observed from the findings of related reviews that the prevalence rate of behaviour problems in children with intellectual disability is higher than normal children. The most common behaviour problems are anxiety, aggression, depression, withdrawal behaviour and conduct disorders and these behaviour problems vary with age, gender and severity of the disability. An association between maternal stress and behaviour problems is also observed. Therefore, mastery in coping with the complex situations, positive parental attitude, attachment to mother, maternal acceptance, conducive home environment can successfully protect and help intellectually disabled children against behaviour problems.

2.2 REVIEW OF LITERATURE RELATED TO MOTHERS OF INTELLECTUALLY DISABLED CHILDREN AND THEIR SELECTED PSYCHOLOGICAL VARIABLES

The researcher selected frustration, alienation, feeling of well being, and emotional intelligence as psychological variables of mothers of intellectually disabled children. The brief of findings of reviewed studies related to these variables have been given in following pages:

Jain (1967) examined the social problems related to the presence of an intellectually disabled child. Results of the study revealed that parental
feelings were marked by anxiety about future. Also negative effects on other siblings, psychological stress, decreased interaction with neighbours and relatives, misunderstandings within family and economic loss were significant facts associated with presence of a child with intellectual disability in the family.

Arya (1970) found that the diagnosis of child’s retardation gave a shock to the child’s parents. Such parents of mentally handicapped child needed professional help. Over attention, anxieties for future, unrealistic expectations from the retarded child led to increased levels of frustrations and loneliness in these parents of mentally retarded children.

McDaniel (1970) observed that rejection and guilt in the parents of mentally retarded children. It was revealed that mothers showed more negative attitude towards their mentally retarded child as compared to their fathers. Mothers felt ashamed and embarrassed due to presence of retarded child which further led to increased level of anxieties, frustration and alienation.

Prabhu (1970) found that parents of mentally retarded children who over-estimated potential of their child were more frustrated, emotionally unstable and had poor adjustment.

Rutter (1970) found that the presence of mentally retarded child in the family brought frequent quarrels between the parents that led to frustration and depression.

Tredgold (1970) found that the mothers of mentally challenged children were under the grab of pity and sympathy. There were also apparent much irritation, resentment, frustration, alienation and burnout in these mothers. The mothers expressed their hostility against fate.

Akhtar and Verma (1972) stated that the problems of mentally retarded were enormous and the role of parents was important. When the parents became aware of defect in their child, they went through various reactions like shock, denial, guilt and emotional maladjustment.
Parshad, Kaushal and Verma (1973) found that mothers of mentally retarded children were more emotionally disturbed and stressed than the mothers of normal children.

McAndrew (1976) revealed that families having mentally challenged children often experienced social isolation. He reported that mother’s relationship with family friends were adversely affected by the birth of mentally challenged children and this in turn affected their psychological well being, made them more depressed.

Kaur (1977) carried out a study to examine the impact of a mentally handicapped child on family. The results revealed the fact that presence of a mentally handicapped child was a source of frustration and burden on the family members.

Massenzio (1977) revealed that parents of intellectually disabled children face many stresses as they had little opportunity to explore their own needs and they had to fulfil consistent caregiving demands of the disabled child, these difficulties led to feeling of alienation, burnout and emotional imbalances in them.

Bhattacharya (1978) pointed that the parents of a retarded child suffered from frustration and anxiety over the question of meeting their child’s needs, which impaired their emotional and social adjustment. The parents felt frustrated as they took the child’s handicap as a blow to their own success as parents, more so because of their unrealistic demands upon the retarded child.

Owens and Birchenall (1979) found that the parents of mentally handicapped child experienced problems in particular areas such as their marriage, physical and mental health, and socio economic status. The over burdened routine and little time for themselves made them frustrated and socially isolated.

Seth (1979) found that 87% of mothers reported inability to carry out household work, 83% reported that their social life was hampered due to loss of prestige, feeling of shame, social stigma and difficulty in visiting others.
Further it was concluded that mothers of mentally retarded children experienced more severe stresses and pathological attitudes than those of normal children.

Jones (1980) indicated that individuals low on self confidence showed general reduction of non-verbal behaviour on most measures. Stress was seen to be associated with decreased social interaction among mothers of mentally challenged children.

According to Srivastava, Saxena and Saxena (1981), mothers of mentally challenged children were likely to be more reserved, homely and apprehensive about their children and consequently did not encourage independence and child’s outgoing behaviour as they felt embarrassed and insecure.

Pain and Nandi (1982) found that mothers of mentally challenged children had more score on psychotism. Mothers of normal children were more extroverted than mothers of mentally challenged children. The findings also suggested that mothers of mentally challenged child were introverted, isolitary, lacked in the feeling of empathy and self confidence, felt frustrated and hostile towards others, and were unconventional.

Sexton (1983) indicated that personality of mothers of mentally challenged children was related to anxiety, low self-esteem, hostility, dogmatism, aggression, loneliness, rejection and low emotional competence.

Drew, Logan and Hardman (1984) concluded that denial, projection of blame, guilt, grief, withdrawal, rejection and acceptance were the usual parental reactions because of their own feeling of insecurity and low self confidence. The siblings also experienced feeling of guilt, shame and embarrassment.

Dutta (1985) revealed that the higher degree of neuroticism among the retarded children indicated a higher level of social isolation, rejection, labelling and stigma in their parents; these negative feelings increased with failures and repeated frustrations.
McDowell, Shea and Bouer (1985) pointed that the parents of a disabled child progress through six emotional stages upon discovering their child’s disability: disbelief, guilt, rejection, shame, denial and a feeling of helplessness. Though reactions to the birth or diagnosis of a disabled child varied from parent to parent, or family to family, people shared common elements. Frequently, the parents’ initial feelings were shock and numbness; parents experienced periods of panic, anxiety and helplessness, as well as periods of indifference and anger, at that time they faced nearly overwhelming depression, apathy and bitterness.

Wilton and Renault (1986) suggested that frustration levels are somewhat elevated in families with pre-school children, the tendency being particularly marked in families with intellectually handicapped children.

Shaw and Emery (1987) reported that parental acrimony increased the level of loneliness among parents of mentally retarded children and it was significantly correlated with children’s behaviour problems.

Minnes (1988) studied the family resources and behaviour problems associated with families having a mentally retarded child. The results of the study indicated that child’s characteristics and family’s crisis for meeting resources were the significant predictors of various forms of behaviour problems in mentally retarded children.

Fishman, Woff and Non (1989) in their study examined the role of parenting stress and parental depression and marital intimacy among parents of disabled children and developmentally normal children. Results showed that mothers and fathers of autistic children significantly showed greater stress and depression as well as marital intimacy than mothers and fathers of children with down syndrome.

Viekie, Harris and Susan (1989) explored the problems experienced by mothers of mentally challenged children and stated that child welfare issues and restrictive time demands were the most intense family problems reported by mentally challenged children’s mothers. All these problems produced negative impact on their emotional state.
Viekie and McHale (1989) revealed that worries about child welfare and consistent care giving demands were the problems reported by the most of the mothers of mentally challenged children and these problems led to symptoms of stress and emotional imbalances.

Bretherton (1990) concluded that positive relationship between the mother and her mentally challenged child was found helpful in making her feel better on emotional level.

Sen and Tuli (1991) studied the agony of parents of mentally handicapped individuals. They revealed that no other type of disability caused as much of personal, family, social and psychological problems as that of mental handicap. Further they indicated that not only mother but all the members of a family were affected psychologically, emotionally and socially; this in turn affected their personality.

Miller, Gordon, Miller and Diller (1992) explored the mediating influences of coping strategies and cognitive appraisals. As predicted, emotion-focused coping was related to increased psychological distress in mothers of disabled children whereas problem focused coping was associated with decreased distress. Both relationships were significant even after controlling for differences in type of parenting stressor. Hierarchical regressions showed that 58 and 25% of the variance in psychological distress was explained by the independent variables; however, the predictors were different for the two groups of mothers.

Prashad (1992) pointed that the mothers high in concern for status of their mentally handicapped child more frequently reacted emotionally and expressed displeasure, sentiments and anger on instance of discrimination and maltreatment to their child. This further resulted in their protests and revolts against the traditional social norms and taboos which place them in inferior position and affected their emotional adjustment.

Gray (1993) found that almost all parents with children with autism felt stigmatized in public situations (for example at the supermarket or a shopping
mall), and that parents of younger and/or more severely disabled children felt more stigmatized and this feeling led to alienation in these parents.

Hallum and Krumboltz (1993) studied the psychological aspects for parents of caring for a young adult with disabilities. Mothers reported significantly more caregiving stress than fathers; a major factor was the persistent limitations in their personal life opportunities and choices at a time when most parents experience freedom from caregiving responsibilities. Contrary to the assumptions of health-care professionals, the parents indicated that they were more anxious than depressed about their future options and their child’s quality of care and future living circumstances. There was no major psychopathology and a review of high scores on the scale of psychoticism and paranoia indicated that the parent’s responses were a reflection of realistic isolation and lack of trust in professional and agency-based relationships.

Beresford (1994) in their study on families with mentally challenged children revealed that such families experienced high level of stress. However, the research also revealed that this stress was inevitable. The nature of stress correlated with several aspects of family life such as daily care demands, emotional distress, maternal depression and anxiety and social isolation.

Rogner and Wessels (1994) observed that mothers of mentally challenged children showed high emotional stress, indulgent in self-criticism, low self confidence and searched for social support in the process of adaptation.

Malhi and Singh (1995) pointed that the parents of children with mental handicap have unique liabilities, their own concept, hopes, ambitions and expectations from their child. Further he added that when parents came to know about disability of their children, their dreams got disrupted, they were badly disappointed and this led to depression and insecurity in them.

Moes (1995) pointed that characteristics that were common among children with autism included scattered intellectual abilities or isolated skills and pervasive problem behaviour such as self-stimulatory behaviours and these characteristics contributed to parenting stress.
Peshawaria, Venkatesan and Menon (1995) found that parents of mildly mentally retarded children reported significantly high emotional reactions. The physical health problems of the family members were linked to these emotional reactions. Parents of children with behavior problems reported more inhibitors related to professionals’ management of their children, such as wrong guidance and problems related to professionals. Professionals required higher technical skills and training to help parents for management of behavior problems of their children and when they failed in managing problems, high frustration was felt by the parents.

Burke and Cigno (1996) found that perceived lack of support from predominantly male partners in the families of disabled children. It was also revealed that fathers sometimes coped, by working away from home. Mothers vented their feelings and had a wider range of emotional expression, feeling grief and sadness in addition to anger and crying. They relied on talking to friends and family as a way of dealing with their emotions, particularly with other mothers with a child with autism.

Kutty (1996) depicted that a family faces threatening or embarrassing behaviour by social isolation and stigma attached to mental illness, self blame, guilt experienced by family members, financial and employment problems and disruption of household routines and social activities which lead to feeling of anxiety and insecurity in them.

Blacher, Shapiro, Lopez, Diaz and Fusco (1997) studied the level of frustration and stress among women who have mentally challenged children. It was showed that these mothers reported more family problems, poorer health, frustration and more negative feelings about parenting their mentally challenged child. This further leaded to stress in them.

Heller, Hsieh and Rowitz (1997) found that in comparison with fathers of intellectually disabled children, mothers spent more time providing care, offered more types of support and perceived more caregiving burden. The behaviour and health of the children had a greater impact on psychological and physical well being of mothers as compared to their fathers.
Barnes, Kroll, Lee, Jones and Stein (1998) emphasized that amount and nature of communication between parents and children about the disability played an important role in mediating the outcomes, both positively and negatively. When children have a disability, families were reluctant to communicate about family difficulties to them and their friends which led to loneliness and negative feelings of stress and frustration.

Browne and Bramston (1998) found that parents of children with intellectual disability reported higher levels of child-related stress than parents of normally developing children. The extra stress of caring for a child with disabilities placed parents at risk of suffering from depression and they also lacked on well being index.

Laible and Thompson (1998) found that emotional laden discourse about a child's past experiences could make emotions more accessible and less threatening for the mother of a mentally handicapped child when reflecting upon past personal experiences (particularly the negatively charged emotional experiences). The results showed significant association between the mother of the handicapped child in reference to the feelings of self confidence and evalutive factor, and attachment security and it was found that a secure attachment was important in fostering the understanding of negative emotions.

Essex, Seltzer and Krauss (1999) examined stress and coping processes among mothers and fathers of adults with mental retardation. No difference between mothers and fathers was found with respect to their frequency of use of emotion-focused coping, but mothers used significantly more problem-focused coping strategies than did their husbands. For mothers, greater use of problem-focused coping strategies and lower use of emotion-focused coping buffered the impacts of caregiving stress on their psychological well-being.

Marika (1999) pointed that presence of a disabled child in the family had adverse effects on the entire family. Results of the study revealed that the
families having a disabled child encountered tendency towards social isolation and affected psychological health of mother.

Hedov, Anneren and Wikblad (2000) found that mothers of children with disability had significantly lower, less favourable scores on well being scale than did the fathers of disabled children.

Seshadri, Verma, Prashad (2000) reported that the mentally challenged child introduced new responsibilities in the family. In turn, this affected the marital harmony among the parents and the amount of stress experienced and parental attitude determined the extent of social and marital stress.

Walden, Pistrang and Joyce (2000) examined a sample of parents caring for their offspring with intellectual disabilities and the factors contributing to their quality of life and experiences of caregiving. Structured interviews were conducted with 62 parents of adults with intellectual disabilities. On several indices of well being, these parents did not seem to be functioning as well as caregiving parents or as well as adults in the general population. The offspring's level of challenging behaviour and physical dependency and the parent's satisfaction with informal support were associated with parental well being.

Hastings and Johnson (2001) revealed that the deficit in emotional expressiveness of autistic children lowered the empathy between mother and child, and thus induced greater parental stress. They revealed that the behavioural, social, and cognitive dimensions of the disorder of disabled child were associated with stress in parents. Also the more severe the child's symptoms, the greater were the degree of parental stress.

Olsson and Hwang (2001) revealed that forty-five per cent of mothers with children with intellectual disability without autism and 50% of mothers with children with autism had elevated depression scores, compared to 15–21% in the other groups. Single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner.
Smith, Oliver and Innocenti (2001) pointed that chronic disability of children changed psychological functions of parents and they faced high level of depression and frustration.

Warfield (2001) found no significant associations between employment status and parenting demands, family support, well being and stress for the sample as a whole. Among employed mothers, those who rated their jobs as interesting reported significantly less parenting stress and moderate levels of feeling of well being when they experienced low or mean levels of parenting demands.

Datta, Russell and Gopalakrishna (2002) pointed that expressed emotion towards the child with intellectual disability predicted a high level of burden among the caregivers and reinforces the importance of focused intervention of guidance to modify the family communication style.

Diter (2002) compared the anxiety, burnout and general psychological symptoms in the mothers of mentally challenged children and the mothers of normal children. The results of the study revealed that mothers of mentally challenged children were reported to be more anxious, stressed, introverted, and neurotic with withdrawal behaviour than normal control group of mothers of normal children.

Gray (2002) carried out a longitudinal, ethnographic study of the psychosocial adaptation of parents of disabled children. It was revealed that most parents experienced improvements in their psychological well-being, the social experiences of their immediate family members and their relations with members of extended family. Changes were also reported in the stressful situations they experienced and their strategies for coping with them. Stigmatizing reactions of non-family members declined. The results were less favourable in the cases of families with aggressive and/or violent children.

Heiman (2002) examined the perspectives of parents of children with an intellectual, physical, or learning disability on the basis of characteristics of family resilience. Thirty-two parents were interviewed as to past, present, and
the modes of coping. The questions examined various aspects of family ecology domains: parents' responses to the child's diagnosis; patterns of adjustment; family support and services used by parents; and parents' feelings and future expectations. Although, it was found that most parents had to make changes in their social life and expressed high levels of frustration and social withdrawal, many tried to maintain their routine life. The majority expressed the need for a strong belief in the child and in the child's future, an optimistic outlook, a realistic view and acceptance of the disability. The study highlighted the importance of social resources and support, and the need for effective programs of guidance.

Emerson (2003) compared mothers of sampled children who did not have intellectual disability and mothers of sampled children with intellectual disability and reported that their child's difficulties resulted in greater social and psychological impact. Also, mental health problems of mothers of children with intellectual disability were associated with the child's difficulties and had greater social impact and unhealthy family functioning which further led to reduced feeling of well being.

Trute and Murphy (2002) found that families were affected by their disabled members in various ways. The results of the study showed that mothers of mentally retarded children felt more depressed as they lacked emotional competence. It was found that parents who were attending the professional support for a longer span of time felt significantly less anxiety and irritability due to the presence of mentally retarded children.

Kim, Greenberg, Seltzer, and Krauss (2003) studied the role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability. It was observed that increased use of emotion-focused coping led to declining levels of well-being.

Russell (2003) pointed that after the diagnosis of a child's disability, parents have to develop new expectations concerning the child, their role as parents and the support services that are designed to meet their needs. Research
showed that these needs frequently remain unmet. Results of the study revealed that little was known about parents' expectations and when parents were informed at an early stage in their experience of parenthood, they interacted more effectively with professionals at a range of levels.

Shin and Crittenden (2003) found that causes of stress for the American mothers were specific to the individual variables and for Korean mothers, cultural values that carry social influence were strongly associated with their experience of stress.

Abbeduto, Seltzer, Shattuck, Krauss, Ormond, Murphy and Floyd (2004) found that the psychological well-being of mothers raising a child with a developmental disability varied with the nature of the disability. Mothers of individuals with fragile X syndrome displayed lower levels of well-being than those of individuals with Down syndrome, but higher levels than mothers of individuals with autism, although group differences varied across different dimensions of well-being. The most consistent predictor of maternal outcomes was the behavioural symptoms of disabled child.

Baker, Blacher and Olsson (2005) pointed that children with intellectual disability were at heightened risk for behaviour problems, and these problems increased parenting stress. Results revealed that parents of delayed and non-delayed preschoolers generally did not differ on depression or marital adjustment, but child behaviour problems were strongly related to scores on both measures. Optimism moderated this relationship, primarily for mothers. When child behaviour problems were high, mothers who were less optimistic reported lower scores on measures of well-being than did mothers who were more optimistic.

Wendelin and Hartman (2005) found that dealing with mental handicap of the child was wrenching for their parents especially for mothers. They revealed that the mothers of mentally handicap children often passed through the emotional stages of grief, denial, anger, frustration and depression.

Glidden, Billings and Jobe (2006) studied personality, coping style and well-being of parents rearing children with developmental disabilities. Results
indicated that parents used more problem-focused than emotion-focused coping strategies. It was found that personality factors, neuroticism especially, was predictive of coping strategy use. Also higher levels of positive reappraisal were associated with higher levels of subjective well-being, whereas higher levels of escape-avoidance were associated with lower levels of subjective well-being, but only for mothers.

Gray (2006) carried out a longitudinal study on parents coping with disability over a period of approximately a decade. The research method for the study was based on in-depth interviews and participant observation. The results of the study revealed that coping strategies changed from the time of the initial study, as fewer parents coped through reliance on service providers, family support, social withdrawal and individualism and relatively more parents coped through their religious faith and other emotion-focused strategies. The results tentatively supported that aging is linked to the use of more emotion-focused coping strategies.

Hastings, Daley, Burns, Beck and MacLean (2006) assessed mothers of children with intellectual disability at two time points, 2 years apart. Data were gathered on maternal distress, mental health, expressed emotion, and the child’s internalizing and externalizing behaviour problems. Consistent with previous research with families of children who have intellectual disability, maternal distress and children’s behaviour problems entered into a bidirectional relationship over time. This relationship was found to be specific to externalizing problems. Also maternal expressed emotion, criticism and not emotional over-involvement was cross-sectional but not longitudinally related to children’s externalizing behaviour problems and to maternal distress.

Laurvick, Msall, Silburn, Bower, Klerk and Leonard (2006) studied the physical and mental health of mothers caring for child with Rett Syndrome. The results of the study revealed that the mother working full time or part-time outside the home, less reporting of facial stereotypes and involuntary facial movements, well adjusted marriage and low stress scores were the factors positively related with better mental health of mothers.
Graungaard and Skov (2007) pointed that parents of disabled children experienced great emotional stress during the diagnostic process and dissatisfaction with disclosure was widespread. Results highlighted the certainty of the diagnosis was central for parents’ experiences. First, the emotional reaction of the parents was highly influenced by the diagnostic process. Second, parents needed possibilities for taking action, and third they found difficulty in coping with an uncertain future. These three themes all related to the meaning that parents ascribed to the stating of a diagnosis. Parents’ needs in relation to communication were identified as equality in cooperation with doctors, an empathic professional approach, and the child being seen with possibilities despite his or her disabilities. Parents wanted to co-operate and they needed possibilities for active coping with their situation.

Lounds, Seltzer, Greenberg, Shattuck and MacLean (2007) observed longitudinal effects of transition and change in adolescents and young adults with disability on maternal well-being. They investigated how change in the characteristics of 140 adolescents and young adults with an autism spectrum disorder would predict subsequent change in maternal well-being and in the quality of the mother–child relationship. Overall patterns of improvement in maternal well-being and mother–child relationship quality were observed during the study. When the son or daughter had declining behaviour problems, mothers' well-being and perception of relationship quality improved to a greater extent. In addition, improvements in maternal well-being and relationship quality were observed in mothers of daughters, in mothers of individuals with mental retardation as well as autism, and in mothers of those in better health.

Minnes, Woodford and Passey (2007) determined whether carer resources i.e. social support and formal service use and carer appraisals of ageing and stress/burden mediate the relationships between (1) maladaptive behaviour and carer depression; (2) carer health and carer depression; (3) maladaptive behaviour and carer quality of life; and (4) carer health and carer quality of life. Results revealed that carer perceptions of ageing and stress emerged as significant mediators of the relationship between carer health and depression.
In addition, perceived carer stress emerged as a significant mediator of the relationship between maladaptive behaviour and carer depression. Resources and appraisals did not emerge as significant mediators in analyses using quality of life as a positive outcome. Results highlighted the important contributions of appraisals to well-being and raised questions for future research regarding the role of resources such as informal and formal support in the coping process.

Norton (2007) in his study on feelings of parents of mentally handicap children revealed that parents, specifically, mothers with high levels of identity ambiguity (which included blaming themselves for their child's mental handicap and holding themselves responsible for their outcome) reported more symptoms of burnout, stress and frustration.

SemNeith (2007) concluded that caregivers of mentally challenged children experienced more financial burdens, more restrictions in social activities, more social isolation, higher parental and marital stress and heightened rates of anxiety and depression as compared with the parents of typically developing children and parents of children with other disabilities. These negative emotions led to frustration, alienation and low feeling of well being.

Vijesh and Sukumaran (2007) revealed that stress experienced by mothers of disabled children was at a moderate level and the pessimism expressed regarding the child’s ability towards achieving self sufficiency, was found to be most stress producing factor. Among the child related and mother related variables, only multiple disability along with cerebral palsy was a significant variable in deciding the difference in the severity of stress among the mothers.

Gammeltoft (2008) explored the roles played by parents living in Hanoi, Vietnam, in shaping the subjectivities of children who are categorized as physically or intellectually impaired. The results identified Buddhist notions of karma, everyday ethics of reciprocity, and party-state discourses of productivity as particularly important forces structuring social responses to human impairment.
Kermanshahi, Vanaki, Ahmadi, Kazemnejad, and Azadfalah (2008) in their study on perceptions of lives with children with intellectual disability found six major themes: challenging the process of acceptance, painful emotional reactions, the interrelatedness of mother’s health and child’s well being, struggles to deal with oneself or the child, inadequate support from the family and the community, and the anxiety related to child’s uncertain future.

Mitchell and Cram (2008) found that parents of children with disabilities were more likely to experience stress and depressive symptoms than parents of typically developing children as a result of the increased challenges inherent in their parenting role. This study investigated the utilization of satisfaction with adolescent health care services reported by mothers and their relation to maternal well-being. The results revealed that both utilization and maternal satisfaction with health care added unique variance in predicting lower levels of maternal stress and depressive symptoms.

Anny (2009) studied the relationship among perceived stress, coping strategies and subjective quality of life of parents having children with severe intellectual disabilities in Hong Kong. The internal coping strategies appeared more likely to be employed to manage the major stressors and they were less likely to sought help from others. The participants had generally lower subjective quality of life with the Personal Wellbeing when compared to the Hong Kong general population. The caregiving stress encountered by the parents were negatively but mildly correlated with the subjective quality of life. Results indicated that the higher the stress encountered by the parents, the lower was the subjective quality of life experience. It was also showed that both the caring stress and the subjective quality of life of the parents were insignificantly correlated with the coping strategies adopted.

Chou, Pu, Kroger and Fu (2010) compared caring, quality of life of employed and non employed mothers of individuals with intellectual disability. Results revealed that non employed mothers are more likely to have a lower level of health status, well being than are mothers employed fulltime. Multiple regression analysis showed that mothers’ well being, quality of life were
significantly determined by the availability of a person with whom they could share care work, family income, social support, and employment status.

Edwardraj, Mumtaj, Prasad, Kuruvilla and Jacob (2010) explored people's cultural beliefs and attitudes about intellectual disability, perceived needs and burden associated with care in Vellore, south India. Results suggested that cultural and religious beliefs perpetuated negative attitudes towards disability. This meant that caregivers bore a high burden of care with little support from family or society. The study confirmed the presence of diverse, multiple and contradictory models of disability drawing from biomedical and local religious, social and cultural constructs. It was concluded that public awareness, education and community-level interventions for reducing the misconceptions and stigma related to intellectual disability are needed in addition to culturally sensitive treatment methods to improve the attitude towards and management of intellectual disability.

Yildirim and Basbakkal (2010) studied socio demographic factors that play a role in depression among mothers of children and adult with an intellectual disability. Results revealed that there was a significant relation between depression scores of the mothers and education level of the mothers and their spouses and financial status of the families. Mothers with insufficient income and lower education levels were found to be at risk of depression and alienation.

Benson, Daley, Karlof and Robison (2011) revealed that emotional strength found to be a significant predictor of child social competence, but not child problem behaviours.

Norlin and Broberg (2012) conducted study on parents of children with and without intellectual disability in relation to couple relationship and individual well-being. The results revealed that marital quality predicted concurrent well-being, and coparenting quality predicted prospective well-being. Mothers of children with ID reported lower well-being than other parents.

It was observed from the findings of collected reviews that consistent caregiving demands, disruption in family routine, disruption in family leisure
and recreation, negative effect on the other sibling, misunderstandings within
the family, loss of prestige, feeling of shame and guilt, social stigma, loss of
expectations, decreased interactions with the neighbours and relatives,
behaviour problems of the child, economic loss, lack of information regarding
disability, lack of resources and guidance from professionals are the
challenges faced by the parents of intellectually disabled children, especially
by the mothers as they act as primary caregivers. All these challenges further
lead to anxiety, burnout, stress, depression, alienation, emotional and
physical health, marital conflicts, frustration and reduced feeling of well being
in mothers of intellectually disabled children. So, review of relevant studies
helped the investigator to include psychological variables namely frustration,
alienation, feeling of well being, emotional intelligence of mothers so as to
examine the effect of treatment of guidance on selected psychological
variables.

2.3 REVIEW OF LITERATURE RELATED TO MOTHERS’ COPING
WITH INTELLECTUAL DISABILITY OF THEIR CHILDREN

Reviews related to mothers’ coping with intellectual disability are presented
below

McCubbin, Joy, Cauble, Comeau, Patterson, and Needle (1980) concluded
that the family’s ability to cope with the specific stressor or crisis depended
upon family resources and included an individual’s personal resources, the
family system’s internal resources of family system, social support and coping
abilities.

McCubbin and Patterson (1983) revealed that the extent to which families
experienced stress depend on many factors including the child’s
characteristics, structure of the family, family resources, and coping
strategies.

Foster and Gallagher (1986) compared the coping behaviour of depressed
and non-depressed mothers of challenged children. They found that
depressed mothers used emotional discharge as a coping technique and had
low emotional intelligence. The non-depressed population consistently rated all methods of coping as more helpful than did the depressed sample regardless of the frequency of use.

Rose (1987) found that having a child with a disability was an event that left many parents feelings they have little control; however, they had significant control over how they reacted and coped with the situation.

Crnic and Greenberg (1990) found that the cumulative impact of daily parenting hassles and difficulties in dealing with mentally retarded children represented significant burden that subsequently affected parent and family functioning. They further revealed that mothers usually shared their experiences of hassles due to children's behaviour, with their friends and these interactions helped in reducing the parenting stress in them.

Purnima (1990) concluded that the problems experienced by mothers of mentally challenged children vary at different stages of the life cycle and this affected mother's coping with their children.

Sequeira, Madhu, Subbakrishna and Prabhu (1990) investigated on coping styles used by the mothers of mentally handicapped children and results revealed that mothers perceived retarded children with larger number of associated problems like lack of concentration, behaviour problems, poor comprehension etc., as more disruptive for routine family activities and hence felt frustrated. They further indicated that denial, rehearsal of outcome, finding a purpose and seeking emotional support were the coping styles commonly used by the mothers of mentally handicapped.

Wood and Flynt (1990) studied the coping behaviour of mothers of moderately mentally retarded children. They found that those mothers of moderately mentally retarded children who expressed greater satisfaction with intimate, availed friends’ support and family support coped successfully with the stressful situations.
Koenig (1992) explored the various strategies used by mothers to cope with the stressors and found that one out of every five mothers reported that religious thoughts or activities were the most important strategy used by them to cope with stressors.

Margalit, Raviv and Ankonina (1992) found that parents of disabled children reported significantly higher avoidance coping, less emphasis on family interrelations, few opportunities in the family for personal growth, and lower coherence than did parents of non-disabled children.

Rowitz (1992) carried out a study on coping strategies used by the families having mentally retarded children. He pointed that mental retardation was a family affair and welfare of the individual with developmental disability was attributable to the different coping strategies used by the family members. Therefore, coping strategies used decided how well the families cope with stressful situations.

Kravetz, Nativitz and Katz (1993) examined how mothers and fathers cope with tensions involved in the day-to-day struggle of raising a child with mental retardation. Although a statistically significant difference was found between mothers' and fathers' use of coping strategies and mothers reported more emotion focused coping.

Ramgopal and Rao (1994) studied the correlation between behaviour disorder and parental coping behaviour of the mentally retarded children. The results of the study revealed that there was a non-significant negative correlation between parental coping behaviour and behaviour disorder of the mentally retarded children. Also, findings showed that anxiety problems were the highest among parents of mentally retarded children.

Terry (1994) emphasized that coping responses were influenced by generalized control belief, individuals having internal control beliefs used more problems focused coping and less emotion focused coping than persons with external control beliefs. Further, he pointed that the coping reaction changed from moment to moment across the stages of a stressful transaction and the style of coping strategies also varied according to the type of situation.
Koo (1995) in his study on parents of normal and mentally retarded children, found that no significant difference in the level of coping was observed between the mothers and fathers of mentally retarded children and mothers and fathers of normal children whereas the fathers showed significantly high scores in coping than the mothers in both the groups. He further revealed that the mothers experienced significantly greater level of general stress than the fathers did in both groups of the retarded and of the normal children.

Pargament (1997) emphasized that even though some strategies have been found to be more effective than others, it was difficult to assess the outcomes of coping because some people strived for different means, and some approaches were helpful in the short-term, but problematic in the long run.

Peshawaria, Menon, Ganguly, Roy, Pillay, and Gupta (1998) studied the facilitator and inhibitors to effective coping by mothers of children with mild or moderate mental retardation. They found that better marital satisfaction or support from the spouse, was an important facilitator to effective coping by mothers. They also emphasized that working out problems on one’s own, self-determination and faith in God were more common facilitators used by parents of children with mild or moderate mental retardation. They further revealed that the two most common inhibiting factors affecting coping reported by the parents of the mentally retarded children were behaviour problems in their children and lack of acceptance of their mentally retarded child. They further pointed that the presence of behaviour problems in mentally retarded children produced greater stress for parents. Management of these problem behaviour required more efforts and skills in handling them and hence social and family supports were considered as important facilitators.

Bailey and Smith (2000) concluded that the personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influenced the coping abilities of a family.

Grant and Whittell (2000) revealed the usefulness of problem-solving, cognitive and stress reduction coping strategies by the family members.
Further, it was concluded that coping behaviour depends on gender, life stage and family structure.

King, Scollen, Ramsey and Williams (2000) highlighted two cognitive coping strategies used by parents of children with Down syndrome: positive reappraisal, which was related to higher levels of subjective well being and blaming others, which was related to more depressive and angry feelings.

Kausar and Farooq (2001) studied the coping strategies employed by mothers of mentally retarded children. They found that mothers of mentally retarded children employed significantly more practical (problem-focused) and religious-focused active strategies to deal with their child's mental disability as compared to the remaining of the strategies.

Lam and Mackenzie (2002) studied the Chinese mothers’ experiences of parenting a child with disability. Results identified seven major themes viz 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. The avoidance, self-reliance, and seeking social support were the strategies frequently used by these mothers.

Taanila, Syrjala, Kokkonen and Jarvelin (2002) found that information and acceptance, good family co-operation and social support were the coping strategies most frequently used by the families. 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.

Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, Murphy and Floyd (2004) found that problem-focused coping was related to less depressive symptoms in mothers of children with down syndrome, autism, or fragile X syndrome, whereas emotion-focused coping was related to more depressive symptoms.
Garnefski, Teerds, Kraaij, Legerstee and Kommer (2004) found that catastrophizing, positive reappraisal and acceptance influenced stress experienced by parents over time. Intervention and prevention programs for parents of children with down syndrome succeed by discouraging parents from catastrophizing the fact that they have a child with down syndrome.

Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta (2005) felt the need for increased knowledge and understanding of how family members cope with their disabled children to provide the basis for future service development. Results indicated that there were many children with disabilities who were included, loved and cared for by their families. A lot of time and money was spent on seeking a cure. The extended family systems were breaking down and the main burden of caring for a disabled family member generally falls on one, sometimes two, female carers. Male members act as gatekeepers, controlling the key decisions concerning the child and the associated resources. It was concluded that CBR should move the focus of their services away from the disabled individual towards the whole family. They further emphasized that it is important to provide accurate information about causes and prevention of impairments, the realities of a cure, support and respite for the female carers, and opportunities for the involvement of fathers. At a conceptual level the data support the philosophy of inclusion, social integration, the importance of trust and respect, and utilizing a holistic approach. These were eminently transferable to other settings.

Herman (2005) explored the coping strategies and support systems that orthodox Jewish mothers utilize in coping with a child with a disability, using a naturalistic, qualitative design with in depth face-to-face interviews. Findings suggested 1) Seeking social support viewed as a hierarchy including family, extended family, parents of other children with disabilities, professionals, and the community. 2) Exposure to disability prior to the birth of the child related to the levels of acceptance. 3) Future concerns focused on socially appropriate behaviour, future vocation, and religious obligations rather than academics and marriage. Coping strategies included focusing on the positive and taking a proactive approach. 4) Unique cultural experiences included religious
acceptance, social support as directed toward religious beliefs, attending synagogue, degree of religious education, comfort level with professionals, and future religious obligations.

Glidden, Billings and Jobe (2006) conducted a study on parents of children with developmental disabilities. The results indicated that positive reappraisal and accepting responsibility was related to higher levels of subjective well being, whereas results for escape–avoidance were adaptive for fathers but not adaptive for mothers.

Stoneman, Gavidia and Susana (2006) indicated that the mothers viewed their marriages more negatively when daily stressors increased. They reported higher marital adjustment when their husbands employed more problem focused coping strategies.

MacDonald, Fitzsimons and Walsh (2007) identified patterns of respite use and coping strategies among family caregivers in a region of Ireland. It was found that likelihood of using respite care was not significantly related to family size and social support. Female carers tended to use more ‘problem solving’ strategies than males. Male carers tended to use more ‘managing meaning’ coping strategies than females, although some strategies were shared across genders. The need for carers to have confirmation of high standards of care and the importance of supporting male carers was felt by the investigators.

Glidden and Natcher (2009) reported that parents rearing children with developmental disabilities encountered stressors that required coping and adaptation. For both mothers and fathers, combinations of personality factors and coping strategies significantly predicted the outcome variables measured 6 years later. However, personality was a better predictor for mothers, whereas coping strategies predicted more variance for fathers.

Shelley, Veek, Kraaij and Garnefski (2009) explored the cross-sectional and prospective relationships between cognitive coping strategies and parental stress in parents of children with Down syndrome. After eight months, stress was measured again. Cross-sectional, using acceptance, rumination, positive refocusing, refocusing on planning, and catastrophizing to a greater extent
was related to more stress, whereas using positive reappraisal was related to less stress. Prospectively, acceptance and catastrophizing were related to more stress, whereas positive reappraisal was related to less stress.

Dabrowska and Pisula (2010) examined the profile of stress in mothers and fathers of preschool children with autism, down syndrome and typically developing children and association between parenting stress and coping style. The results indicated a higher level of stress in parents of children with autism. Mothers of children with autism scored higher than fathers in parental stress; no such differences were found in the group of parents of children with Down syndrome and typically developing children. It was also found that parents of children with autism differed from parents of typically developing children in social diversion coping. Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task-oriented coping was the predictor of parental stress in the sample of parents of typically developing children. They highlighted the relationship between coping styles and parental stress.

Gona, Mungala, Newton and Hartley (2011) investigated the challenges encountered by carers of children with disabilities and the mechanisms of coping with these challenges while caring for children with disabilities in a poor rural setting in Kenya. Fear for the future, stress, rumour-mongering and poverty were encountered by carers. As carers grapple with lost expectations, they develop positive adaptations in the form of learning new skills, looking for external support and in some cases searching for cure for the problem. For emotional stability, carers applied spiritual interventions and sharing of experiences.

Woodman and Hauser-Cram (2012) reported that mothers frequently used strategies of denial and planning but rarely use strategies of mental and behavioural disengagement to cope with recent stressful situations. Adolescent behaviour problems were found to contribute to greater symptoms of depression and lower feelings of parenting efficacy as well as increases in depressive symptoms over time. Mothers of sons, but not daughters, reported increases in parenting efficacy across their child's adolescent period. Above
and beyond adolescent factors, several coping strategies emerged as significant predictors of mothers’ symptoms of depression and perceived parenting efficacy. Moreover, use of Active Coping/Planning, Positive Reinterpretation/Growth, and Behavioural/Mental Disengagement as coping strategies moderated the impact of adolescent behaviour problems on maternal depressive symptoms.

John (2012) assessed stress among mothers of young children with intellectual disabilities in urban India and examined the extent to which child functioning and maternal coping predict maternal stress. The study identified negative and positive dimensions of Indian mothers’ caregiving experiences. Three-fourths of the sample obtained a clinically significant stress score, and maternal coping emerged as a robust predictor of stress for mothers of boys with intellectual disabilities. Results indicated positive and negative maternal experiences related to self, child, family and community.

It was observed from the collected reviews that coping strategies used by parents intellectually disabled children decide how well they cope with stressful situations as they differ in initial experiences, personal characteristics, internal control beliefs etc. These parents used problem focused as well as emotion focused coping strategies, and some commonly used coping strategies included denial, avoidance, positive reappraisal, rehearsal of outcome, finding a purpose and seeking emotional support, support from the spouse, religious and spiritual engagements and support from family and professionals. Most of the parents of intellectually disabled children felt that they have little control on adverse effects of the child’s disability on family life however; they can have significant control over how they react and cope with the situation. So, review of related studies helped the investigator to select ‘coping’ so as to provide treatment of guidance to mothers so that they can improve their coping abilities to lead a healthy life with their children.
2.4 REVIEW OF LITERATURE RELATED TO GUIDANCE TO MOTHERS FOR COPING WITH INTELLECTUAL DISABILITY AND ITS IMPLICATION ON BEHAVIOUR PROBLEMS OF THEIR CHILDREN

Tavormina (1975) studied the relative effectiveness of behavioural and reflective group counselling with parents of mentally retarded children. Results indicated that both types of counselling had a beneficial effect relative to the untreated controls; however the behavioural method resulted in a significantly greater magnitude of improvement. The behavioural technique was the treatment of choice for counselling parents of the retarded.

Haan (1977) found that the parents of mentally retarded children faced many special stresses. They had been offered information about their children but little opportunity to explore their own needs and difficulties. Such an opportunity was offered to parents, as couples, in group settings and it was found that such guidance through group therapy brought improvement in parents.

Biswas (1980) pointed out that parents generally felt ashamed of their mentally challenged offspring because of reactions of others. They withdrew themselves almost completely from the community activities because of the presence of mentally retarded child in the family and hence required proper guidance to well adjust in family and the society.

Hampson and Tavormina (1980) described group parent training procedures for foster mothers, half trained in behavioural child-rearing skills and the other half given reflective group counselling for eight weeks. Comparison of the two modes of training showed that reflectively counselling brought improvement primarily in parent attitudes, whereas behaviourally trained parents improved primarily in actual use of appropriate behaviour skills and reported reductions in problematic child behaviour and improvement in overall family environment.

Ian and Wood (1981) evaluated the parent intervention with young handicapped children. They concluded that parents guided by behavioural methods led to positive changes in child and parental well being.
Hornby and Murray (1983) conducted programmes with groups of parents of school-aged, physically handicapped, hearing impaired and mildly and moderately mentally handicapped children. Findings indicated that group programmes were valuable for parents. An integral part of the parent programmes had been the training of special education teachers in the attitudes and coping skills necessary for working with parents of handicapped children. The introduction of group programmes was considered to complement the individual training and counselling services already available to such parents in New Zealand.

Hornby and Singh (1983) reviewed the behavioural group guidance studies with parents of mentally retarded children with a special emphasis on methodology. They revealed that all studies reported favourable training outcome and the group training modality was a more economical and practical approach than individual parent guidance.

Curran (1985) concluded that families who handle stress effectively, worked together to find solutions, shared responsibilities, communicated, shared their feelings with one another, and felt good about them at the end of guidance program.

Veena (1985) studied the management problems and practices of home makers with a disabled member in the family. She revealed that the nature and extent of disability of the disabled member affected the problems faced by the family, therefore guidance needed for management of behavioural problems and to overcome the burden of caring a disabled member.

Sigel (1986) pointed that guidance improved parental knowledge about the process of child development that influenced the way parents understand the behaviour of the children. This further increased parental well being and affected the parent-child interactions, which in turn further affected behaviour problems of the children.

Donovan (1988) indicated the group differences among mothers were found on family stress. All comparisons of child related stress revealed that mothers
with a autistic child perceived greater level of family stress than did mothers with a child who had mental retardation. He further revealed that when the demands associated with parenting mentally retarded children exceed the resources of the family, mothers decided to cope by actively seeking support, advice and help outside the family system.

Mann (1988) revealed that the working mothers of mentally retarded children were highly frustrated and stressed as compared to those of non-working mothers. Intervention provided to them led to better adjustment in them.

Malhotra (1990) discussed the psychiatric problems in mentally challenged children and their helplessness and inability to express their difficulties due to lack of guidance. The importance of parents, relations, teachers and psychiatric social workers was revealed by initiating group intervention in mentally challenged children and their family members.

Girimaji (1993) discussed the advantages of the home-based family care approach to mental retardation that has gained worldwide recognition and attention. It was emphasized that there was need to work with families to ensure optimum care and successful family adaptation. Approaches to such family interventions included parent education and training, parent guidance, family adaptation and interactive transactional modules.

Khokhar and Khokhar (1995) emphasized that training through scientific method to the mentally challenged children showing deficit skill behaviour, led to self-dependence in them. Techniques of teaching skill behaviour such as shaping, modelling, imitation and token economy were discussed. Physical restraint, response cost, extinction and ignoring have been emphasized for alleviating problem behaviours. Parents need for guidance for the same was felt.

Parkash and Kalpana (1996) compared the differences in attitudes and child rearing practices of mothers of mentally challenged children and those of normal children. It was concluded that imparting information about parental or more specifically mother's child rearing attitudes, by organizing orientation
and guidance programmes for parents of mentally challenged children before they assumed parental responsibility, played an important role for proper handling of mentally challenged children and their problems.

Ray (1996) highlighted the importance of early diagnosis, early intervention and training in enabling a mentally challenged child to lead a better life. The study assessed different types of social and emotional problems of parents of mentally challenged children. Proper guidance, education and training in enabling a mentally challenged child were found to be important to lessen the burden of parents regarding the uncertain future of their mentally challenged child.

Brinchmann (1999) studied the importance of assessment of familial stress due to presence of developmentally disabled child. He found that assessment of parenting stress was important not only to assist mothers and fathers with their own psychological distress but also to guide the provision of needed psychosocial, educational and health guidance that would strengthen family coping and positive adjustment. He also revealed that the reduction of parenting stress led to enhancement of a child's family life and in the child's ultimate integration within society.

Rajendran (1999) emphasized the importance of role of parents in ensuring that their handicapped children lead a normal life and hence proper guidance was given to ensure a normal life of disabled child and his family.

Russell, John and Lakshmanan (1999) assessed the efficacy of interactive group psycho education on measures of parental attitude towards intellectual disability in southern India. The intervention group had a statistically significant increase in the outcome scores and clinical improvement in the total parental attitude score, orientation towards child-rearing knowledge towards intellectual disability and attitude towards management of intellectual disability, but no change in attitude towards the intellectual disability subscale. It was concluded that Interactive group psycho education was effective for changing the attitude of parents with intellectually disabled children, and is a viable option to be developed in situations where resources are limited.
Tennen and Affleck (1999) indicated the importance of attending guidance programmes. They concluded that guidance benefited in better adaptation to challenging circumstances of mentally retarded children and improved emotional competency.

Chadwick, Beecham, Piroth, Bernard and Taylor (2002) suggested that respite care provided relief to the parental burdens. The findings suggested that parents were experiencing 'good' to 'excellent' quality of life and that demand exceeds supply. More work needed to be carried out to establish what services are deemed most valuable to parents and to show how their needs can be met to the best of the Health Service Providers ability.

Lam and Mackenzie (2002) found that parents especially mothers of mentally retarded children felt more emotional stress. They further pointed that the parents who were attending the counselling and guidance programmes for a longer duration felt significantly less frustration, alienation and burnout.

D'Cruz (2003) pointed that family focus in interventions for health and illness at all levels of prevention and at all stages of the health-disease continuum was beneficial. It was highlighted that such interventions were well established in the West but the same was not true of India. Adopting a family focus in India’s health care system should be treated as an urgent matter and acted upon forthwith.

Gawali (2003) studied the impact of psycho-legal intervention on parental involvement in rehabilitation of mentally challenged children. She administered Family Needs Schedule on the parents of mentally retarded children followed by intervention process useful for rehabilitation of mentally retarded children through videotapes. The results indicated positive impact of such interventions on the rehabilitation of mentally retarded children and their families.

Mamta and Punia (2003) indicated that parents had high and moderate knowledge on all aspects except facilities available for their mentally challenged children, and the need for guidance to the parents was realized.
Also it was found that socioeconomic status and residential area had significant influence on the knowledge of parents.

Nystul (2003) viewed guidance and counselling as a process by which one person (the counsellor) helps another person (the client) more effectively not only with his inner world of feelings but also with the stresses imposed by the impact of other people and his physical environment. He also suggested that the effective guidance is not predicted on guess work or hunches but is and should be based on best scientific knowledge at disposal.

Adams, Edelson, Grandin and Rimland (2004) found many parents overwhelmed by fear and grief, for the loss of the future they had hoped for their mentally challenged children, as they did not expect to have a child with a developmental disability. Further, joining parent support groups and guidance services helped parents to learn about treatments that benefited parents at emotional levels as well as their children.

Erickson (2004) concluded that parents of mentally challenged children managed to seek guidance and help for educational, financial and emotional support systems in addition to help given by a team of medical and therapeutic specialists. They were contacted for possible finding options to seek help and guidance related to mental retardation of their children.

Hastings and Beck (2004) pointed that parents of children with intellectual disabilities were at increased risk for stress and other mental health problems. They revealed that guidance through standard service models helped in reducing parental stress. They further provided evidence for effectiveness of cognitive behavioural group interventions as these brought reduction of stress in mothers.

Green, Davis, Karshmer, Marsh and Straight (2005) indicated that guidance programs helped the parents of mentally challenged children to understand their child's condition better and communicate with them in a way they could understand. This better parent-child interaction reduced their frustration and emotional imbalances.
Herring (2005) pointed that parents of mentally challenged felt frustrated due to the mental and financial burdens associated with caring of disabled child. Results indicated that guidance helped the parents of mentally challenged children to learn more by being fascinated by their life than they by being frustrated by it.

King, Zwaigenbaum, King, Baxter, Rosenbaum and Bates (2006) observed that guidance programmes reduced frustration, which resulted from a mentally challenged child being misunderstood due to his mental illness and removed the desperation and helplessness which parents of such children sometime felt.

Chengappa and Oomen (2007) revealed that mothers of children with behaviour problems experienced significantly higher levels of psychological distress. Findings suggested that the quality of parenting contributed to behaviour difficulties and highlighted the need to examine closely the role of parenting behaviour and parental well-being in shaping the course and treatment outcome for children with behaviour problems.

Kaur (2007) emphasized that the psychological well being, physical health and frustration of the mothers of mentally challenged children should be met with friendly approach through proper guidance that may reduce their level of stress. Findings revealed positive effect of guidance for stress management on frustration and burnout in mothers of mentally challenged children. Mothers who received guidance showed less frustration and burnout than mothers who did not receive guidance.

Sapra, Banerjee, Gulati, Kabra and Kaira (2007) identified children with psychosomatic illnesses and managed them with behavioural intervention which included reassurance to the parents and children, relaxation exercises, self hypnosis, repeated sessions of counselling and time management. Forty-nine out of fifty-one children were found to be symptom free on follow up.

Singer, Ethridge and Aldana (2007) conducted a research on group intervention for parents of children with developmental disabilities, in order to
characterize the efficacy of treatments in reducing depressive symptoms and other forms of psychological distress associated with stress in parents of children with developmental disabilities. Consistent positive benefits were found in the form of reductions in parents’ distress and improvement in emotional level and it was claimed that there were established evidence-based interventions for reducing psychological distress at least in middle-class mothers in the short term and the interventions for fathers were promising as were the data on somewhat longer-term effects. Further it was concluded that multiple component interventions addressing both parent well-being and behavioural parent training were significantly more effective than either behavioural parent training or cognitive behavioural training.

Singh, Devi and Kumar (2007) in a study on parental awareness about concessions and benefits for persons with mental retardation pointed that majority of mothers having intellectually disabled children were not aware of the amenities provided by the government. These mothers reported improvement in behaviour of their children after receiving guidance from psychological rehabilitation service agencies.

Pottie and Ingram (2008) found that social support affected the strength of the relationship between stress and mood for parents of children with autism.

Bilgin and Gozum (2009) conducted a study to examine the effect of participating in an education program on burnout for mothers of children with an intellectual disability. Mothers with an intellectually disabled child are prone to suffer from excessive stress and burnout. After baseline screening, mothers who agreed to participate were randomized to an intervention or control group. The intervention group participated in an interactive education programme for 1 hour, in addition to using an educational booklet designed and presented by the researchers. The booklet contained information about the characteristics of intellectually disabled children, the specific health care and education they require, non-profit organizations and foundations providing assistance, and ways in which mothers can cope with stress. The control group received the same intervention separately after completing the post-test. Intervention group members reported fewer episodes of emotional
burnout compared to the control group, indicating that participation in a nursing education programme reduced the level of burnout experienced by mothers who have an intellectually disabled child. There were no effects of the education programme on perceptions of personal success, i.e. mother’s feelings of competence and successful achievement in care of their intellectually disabled child.

Caples and Sweeney (2011) found that the use of respite care services by parents with a child/adult with an intellectual disability in Ireland was growing in the context of social policy initiatives for greater social inclusion of people with disabilities. Irish parents who cared for their child/adult with an intellectual disability at home were not asking for the care of their child/adult to be taken away from them, but to assist them in this role and to help them to meet the demands of personal, family, social and work life, they need to be supported with reliable, flexible and responsive services. Parents often negotiated complex barriers to access support services such as respite, health or social care.

It was observed from the related reviews that intellectual disability is a family affair, welfare of the intellectually disabled children and their parents was attributable to the different coping strategies used by the family members especially the mother. It was also observed that the mothers’ coping is positively correlated with their children’s constructive behaviour and negatively with their children’s behaviour problems. The coping strategies used by mothers decide how well they cope with stressful situations. Therefore, guidance and support from professional, social support, realistic expectations, support from extended family and friends and positive outlook can help mothers to improve their coping abilities, which further may have implication on behavioural problems of their intellectually disabled children.

Thus, review of related studies helped the investigator to select treatment of guidance to mothers for coping with intellectual disability and to examine the effect of treatment of guidance on psychological variables namely frustration, alienation, feeling of well being and emotional intelligence of mothers and its implication on behaviour problems of their intellectually disabled children.