Chapter 2

Review of Literature

The present chapter aims to put forth a detailed review of literature on the issues related to children with intellectual disabilities and their caregivers. These include the socio-economic profile of the parents, various problems faced by them during the upbringing of their child with intellectual disability. It also includes studies related to the level of awareness of the caregivers regarding the disability of their child, availability and utilization of various family and state support systems in Chandigarh and Melbourne. It covers the studies related to social support i.e. family and state support available to the caregivers and their children with intellectual disability. It is anticipated that this review will facilitate to comprehend the various issues of concern related to children with intellectual disability and their caregivers. The review shall, to a great extent draw the attention of the researchers towards the variables related to the topic already investigated and the ones that need to be undertaken to synthesis, gain a new perspective, rationalise the significance of the problem taken up and identify methodologies and techniques already used.

For the purpose of present research, this chapter covers a wide range of studies conducted abroad and in India.

2.1 Studies conducted in India

Sen (1988) in her book on “Psychological integration of the handicapped: A challenge to the society” stated that in all situations except the handicapping one, needs of persons with disability are same as the ones without disability. The attitude towards disabled in India is either indifferent or sympathetic. People tend to interpret disability as ill fortune and also believe that persons with disability do not possess any capacity or potential apart from impairment. The problem they face within the family are as time involvement of family members, sibling issues leading to strain and resentment. Despite all this parental involvement is significant. The author also listed the societal responses towards disability such as fear, avoidance, hatred or sympathy.

Singhi et al. (1990) in their study on “Psychological problems in families of disabled children” put forth that caring for a child with intellectual disability requires extraordinary time; practice is a never ending responsibility. Since providing care for a long period of time can lead to severe health and financial troubles among the
families. Thus parental caregivers need to learn to deal with feelings of shame, depression, and detachment from society and other issues related to their children’s future.

Marshak and Seligman (1995) in a book on “Mental retardation in India” explored that the impact of children with disabilities on parents and other family members has long been of attention to professionals. Accepting of relationships within the family has grown significantly over a period of time. Families are now viewed as interactive, interdependent systems with individual members equally affecting each other. Anything which affects one member of that family is bound to have some impact on all other members thus affecting the family as a whole. Research has documented that the child with mental retardation may also influence functions related to meeting basic family needs, daily care needs, recreation needs, socialization needs and self identity needs.

Rangaswami (1995) in his article “Parental attitude towards mentally retarded children” said that very often the parents have a depressing attitude towards their child with disability. Most of the parents are overwhelmed with feelings of pessimism, resentment and embarrassment. This study observed approach of mothers towards their mentally retarded children with and without behavioral problems. Sample included forty mothers. Out of which twenty mothers had children with behavior problems such as destructive behavior, conflict and fighting and twenty of them had children without behavioral problems. Mother’s attitude was judged through parental attitude towards problem children scale. Results showed that attitudes of mothers of intellectually disabled child with and without behavioral problems varied considerably. Mothers who had children with behavioral problems were high on negative attitude.

Peshawaria et al. (1998) in their article “A study of facilitators and inhibitors that affect coping in parents of children with mental retardation in India” examined both facilitators and inhibitors which affect the coping mechanisms used by parents who have children with mental retardation with a view to provide directions for the establishment of rehabilitation services in the future. The sample was drawn from Delhi, Thiruvanthapuram and Bhopal among parents with mentally retarded children. The sample consisted of two hundred and eighteen parents. Each of the parents was asked two open ended questions and the interviews lasted for about fifteen to thirty minutes each. The data from the sample of two hundred eighteen parents were
analyzed using percentages and chi square tests. The results indicated that parents reported physical support from within the family and outside the family as the most important facilitator followed by professional support. Some other facilitators included financial support, trust in God, working out troubles on one’s own, and self determination. When some other facilitators were tested, the parents reported outer supports provided by others as a better facilitator than their internal coping skills such as trust in god, working out problems on one’s own, self determination and inspiration from spouse or guru. Some of the parents also reported that nothing had helped them to cope with their current situation. In addition to this it was found that behavioral issues of children created enormous pressure among the parents. In order to handle such situations they needed more effort and support from other sources which are considered as significant facilitators. Parents having mentally retarded children with behavioral issues also reported to have shared support from partner and physical support from family as very significant facilitators. The two most common inhibiting factors affecting coping reported by some parents were behavior issues in their children and lack of acceptance of their mentally retarded child, predominantly by paternal grandparents, friends, neighbors, relatives and some others in the society. Apart from the above two, financial constraints and problems associated to professional’s which included wrong guidance about the child’s condition, carelessness on the part of hospital at the time of delivery and inadequate time devoted to the child. These proved to be some common inhibitors. This study also provided some guidelines to ascertain rehabilitation services and classify some challenges for the service providers as well.

Dalal and Pande (1999) in their investigation on “Cultural beliefs and family care of the children with disability” included attitudes of rural Indian population towards physical disability. Research was conducted on equal number of respondents drawn from families having a member with a disability and with those having no member with disability. Interviews were conducted to study disability related attitudes, perceptions and practices. The results revealed fatalistic attitudes and external reliance in families who had disabled children. They expected external agencies to cater to their rehabilitation needs.

Aluri and Karanth (2002) in a survey on “Rehabilitation facilities available for children with autism” collected information on rehabilitation services available for children with autism in Bangalore city and found that there were very few
services available for children with autism. The study reported that most parents initially, consulted pediatricians regarding their child’s problem and found it very helpful. According to them professionals such as psychologists, speech pathologists and special educators were often consulted latter. Parents also reported that early referrals to these professionals for suitable intervention had proved very useful which encouraged them to participate in the intervention programmes being planned for their child. Maximum services availed were for behavioral, communication and medical management. Though these services were not available at one centre.

Tamara (2004) did a research on “From symptom recognition to diagnosis: Children with autism in urban India” The study provided statistics on the process of initial symptom recognition, looking for help and initial diagnosis of a pervasive developmental disorder among ninety five families of autistic children in India. Data was collected from families located in four major metropolitan cities in India and respondents consisted of mothers, fathers and relatives. The data was also collected from professionals such as psychologist, psychiatrists and pediatricians. Sixty percent of the households were nuclear families. The off spring with autism at the time of interview ranged in the age between two to twenty seven years. Fourteen families in this sample first received a diagnosis of autism from outside India. In order to complete the data, a standard procedure was followed in obtaining children from schools. Parents were contacted by email or phone and informed about the purpose of the study. They were asked the general questions related to pregnancy, birth of their autistic children, their concerns, expectations and awareness about autism. Apart from this children were observed at home, at school, temple, restaurants, market and other family member’s homes. The findings recommended that some specific symptoms that the parents initially recognize may be associated with the speed with which they receive a diagnosis. Various factors such as environmental, cultural and socioeconomic factors also had an impact on whether parents receive diagnosis or not. It also said that in all the developing countries, in which autism has been described, India has larger literature on the autism disorder and various terms used to describe this disorder. It was also reported that they first noticed something different when their child ranged in age from three months to six years. Some parents noticed typical autistic features among their children whereas others felt it was normal if some of the developmental milestones are delayed. Results also stated that when parents sensed some difference in their child, they often waited to see whether it could be resolved on
its own or sometimes parents consulted other family members, religious leaders, friends’ latter consulted psychologist, pediatrician and other professionals. In the current study parents waited as long as two years before seeking help from a medical professional. A psychiatrist even explained that in India children with autism or autistic behaviors are seen rather late and hence the diagnosis is not very difficult. Though the primary professionals providing diagnosis of autism were psychiatrist or psychologists, however the parents tend to run around general practitioner, neurologist or other specialist. In addition this, in India, autism is rarely diagnosed, missed or misdiagnosed as mental retardation during the initial visits to doctors. As a result they are unable to receive early diagnosis. It was noticed in previous studies and was also observed in the current study as well that there is a tendency among Indian parents to shop around for health related concerns. Another significant environmental consideration in the process of help seeking and diagnosis of autism in India is that parents tend to travel from one place to another regardless of how far it is, in order to know the diagnosis. The other factors affecting the diagnosis of autism, include the cultural factors which may have direct effect on whether parents receive a diagnosis is the degree to which they feel compelled. Sometimes the parents tend to seek out the most prominent doctors in their area for diagnosis. Where socio-economic factors are concerned, there is a belief in India that families of lower socio-economic background and with lower level of education are not as sensitive to developmental difficulties and may not pick up the symptoms as readily as others with higher education. On the other hand increased access to internet is likely to affect the patterns of help-seeking behavior and diagnosis in India. They are likely to change more rapidly in the coming years than they have been during the lives of many of the children in the current study.

Gupta and Singhal (2004) in their study “Positive perceptions in parents of children with disabilities” put forth the positive perceptions in the parents who have children with disability. It has been found in many studies that children with a disability often face chronic stress and have negative impact not only on the parents but also on the siblings and other family members. In countries like India where people still believe in karma and consider disability as a tragedy or a curse. In spite of these facts this study highlighted positive perceptions regarding raising a child with disability which proved to be very helpful for the families and lead to better adjustment. Researcher also stated that having a positive attitude proved to be an
effective coping strategy for parents. Though the parents stated that they have lost their friendships as a result of having a child with disability however at the same time they looked at the positive aspect and realized that they had developed new contacts and had developed good relationships with health professionals and with the workers who work in the field of disability. Some parents also felt that their emotional bond as husband and wife got stronger as a result of parenting a child with disability. They felt the child brought joy and happiness in their lives and gave them an opportunity to learn and develop new skills. These positive perceptions had a significant role to play in the coping process and strengthening them to handle the stressful events. Many studies also found that parents who were involved in parent to parent support groups had more positive perceptions of their child’s disability.

Gathwala and Gupta (2004) conducted a study on twenty families, entitled “Family burden in mentally handicapped children”. Each family had one mentally handicapped child. There were nine boys and eleven girls. Eighteen children were between the age of five and fifteen, two were beyond fifteen years. The highest score representing the severest burden was obtained for the item which covered the effect on physical wellbeing of other family members followed by burden on family vacation and effect on family communication. The least score was obtained for financial trouble, five the families having ceased to intermingle with friends and neighbours or had become isolated. Since no family is prepared for the presence of a mentally handicapped child. Therefore the presence of a disable child shakes the whole family. In this study too child with disability somewhere effected the families as a whole.

Lee et al. (2005) carried out the study to examine “Indian family adjustment to children with disabilities.” and explored the community response of how American and Indian families adjust to having school age children with disabilities in two varied communities. Community assessment interviews were conducted with one hundred and forty three community members who have school going children with disability in age group of five to twelve years. The diagnosis of a disability was made by medically trained staff. Children were having a diagnosis of learning disabilities, muscular-skeletal disorders, visual and hearing impairments, mental and cognitive disorders and mental health disorders. The Community Assessment interview schedule was developed to gather information on the community’s viewpoint of families caring for a child with disabilities. The schedule had eleven open-ended
questions. Interviews were handwritten and audio-tape recorded. The findings suggested that all families were described as adjusting to having a child with disabilities in constructive and limited ways. Some families considered that the child with disability was given to them for a reason. Thus they included their children in everyday family activities such as going to the store, eating dinner together, attending ceremonies and going to social gatherings. They felt these behavior patterns helped the families to function more smoothly. On the contrary the limited adjustment families felt out of balance, strained and the purpose of having the child did not seem clear. The families were neither able to identify the needs of the child with disabilities nor were aware of how to bring modifications in their life styles so that the child could be cared for. They were not be able to identity all the needs of the child with disabilities and children were not able to reach their full potential. At times were even at risk of neglect and child abuse. Overall these families to some extent were out of harmony and needed support to regulate and come back to their normal functioning.

Gupta and Singhal (2005) worked on “Psychosocial support for families of children with autism” drew attention towards the strain levels and coping techniques used by the families which included mother, father and sibling of a child with autism. The paper also highlighted the significance of providing psychosocial support to the families of children with autism. It was found that almost all parents who have children with autism felt stigmatized in public situations, feeling of loss of personal control, absence of spousal support were also there. It was found that mothers of children with autism would easily become upset and disappointed with their child because of lack of professional activities to keep their child busy and were also anxious about their dependency. Above all, problems associated with siblings put extra strain on the parents which pushed them to take a help from professionals such as physicians, therapists, and others who had expertise in working with the children with disabilities to determine what they believe are the best services for their children. Traditionally intervention for children with autism involved a therapist who used to be responsible for all training programmes for the parents. However, involvement of the parents in the intervention programmes is now increasing. The professionals educate and train the parents to plan individualized treatment and management programmes for their child, which they felt was quite useful. According to them training parents as therapists, broadened the quantity of services for children’s intervention programmes. Apart from that, a key worker is assigned to a family whom the parent
can approach for any advice about any problem related to their child. It was also found that parents used various coping techniques to alleviate stress which include positive attitude, social support, faith in God and religious support. India’s scenario of autism was also discussed in this study where it said that currently, all the needs of children with autism in India, were not met in either the regular or special education system. The awareness about autism is rising, but the accessibility to the services is little. It was felt that there is a need to develop effective service to the providers, who are enthusiastic to deal with the person, the family and society at large.

Chandrasekar (2006) has discussed in his paper on “Persons with disabilities in India-A compilation”. Census of India(2001) reported the population of India as one thousand twenty seven (in million) and the total number of disabled in India was reported to be twenty one million which constitutes more than two percent of total population. Nearly one third of the disabled persons acquired disability since birth depicting impact of genetics, imperfect gene transformation, congenital defects, and unsuitable services at the time of delivery, low level of diet and healthcare provided to the pregnant mothers during their pregnancy period. Both rural and urban areas reported around thirty three percent disability cases since birth. Almost seventy percent of the causes of disabilities in India are due to infectious diseases, serious sickness during childhood, polio, ear discharge, eye diseases aggression and untreated diseases/injuries. Poverty was observed as one of the significant cause of disability in India. Road traffic injuries were also one of the causes of disabilities. It said seventy million disabled people in India could not step out of their homes because of an inaccessible physical structure and transport system. They are not only completely dependent on their families but are also considered to be a burden on society. The culture of the community also influenced the attitudes, beliefs and values to a great extent. It further decided the status of person with disability in the society. It also said that persons with disabilities maybe socially debarred due to the attitudes of fear and lack of knowledge on the part of non-disabled people, who at times also used negative a language to address them. This paper also gave an elaborate sketch of the four legislations to promote and protect rights of the persons with disabilities. These included-The Mental Health Act of India-1987, Rehabilitation Council Of India Act, 1992, The Persons with Disabilities, (Equal Opportunities, Protection of Rights and Full) Act,1995 and National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mentally Retardation and Multiple Disabilities Act,1999. Apart from this it
threw light on benefits/rules for persons with disabilities in the areas of education, health, rural development and other sectors. It concluded on the note that the situation of disability in India is changing gradually.

Vijesh and Sukumaran et al. (2007) in their research on “Stress among mothers of children with cerebral palsy attending special schools” drew attention to the stress experienced by mothers of children with cerebral palsy attending special schools in Kerala state of India. Stress levels were assessed using the local language version of the questionnaire on resources and stress. The data was analyzed with respect to certain child and mother related variables. The tools included case sheet record and questionnaire on resources and stress. The case sheet record was prepared to collect general information about the child with cerebral palsy and his/her family i.e. from the mother of the child. This included information such as child’s name, sex, age, birth order, type of cerebral palsy, religion, presence of multiple disabilities, name of the school that the child is attending and locality of residence. In addition, details of mother, such as age, educational status, occupation, monthly income, type of family were also collected. The questionnaire on resources and stress measured the impact of developmentally delayed or chronically ill child on other family members. The tool measured the four broad categories which included parent and family problems, pessimism, child characteristics and physical incapacitation. The respondents were asked to provide true or false answers concerning their children and family. This study pointed towards the fact that irrespective of the differences in child related and mother related variables, the level of stress in mothers of children with cerebral palsy is almost the same. This may be due to the non-progressive nature of the condition. Another reason for this can be that all the children who study in special schools and their mothers think positively in the hope that their children will attain some level of independence. For any parent, the maximum stress producing event in their life is that time when they realize that their child is disabled. For all the mothers who participated in this study, this realization had happened long ago. Apart from this among the child related and mother related variables, only multiple disabilities along with cerebral palsy is a significant variable in deciding the difference in the severity of stress among the mothers. This study also gave suggestion on how the stress levels can be minimized among the mothers. Similarly, McDowellG, SheaTM and Bouer in their study “Parents and Teachers of exceptional students” stated that generally, parents of a disabled child progress through six emotional stages upon discovering
their child’s disability. These are disbelief, rejection, shame, denial and a feeling of helplessness. The reactions to the birth or diagnosis of a child with a disability vary from parent to parent, or even family to family. Frequently, the parent’s initial feelings are shock, numbness, periods of panic, anxiety and helplessness apart from feeling of indifference and anger thus leading overwhelming depression, apathy and bitterness.

Singh et al. (2008) in their note “Impact of disability of mentally retarded person on their parents” attempted to study positive and negative impact on the parents so that parents can handle their troubles in the best possible way. The study was conducted at the outpatient department of PGI Raipur and two special school of mentally retarded children. Two tests Vineland Social Maturity Scale and Developmental Screening Test were administered to evaluate children’s and parents intelligence. The present study highlighted both positive and negative impact on parents who have children with intellectual disability. The objectives of the study were to examine nature and degree of impact on the parents having child with mental retardation, impact on the family members and the relationship within the family. The study acknowledged the dependence for family intervention programme, at the same time assessed programmes and lastly studied nature and impact with regard to relationships outside the family. In order to complete this study parents of sixty five intellectually disabled children were taken. The mean age of the parents ranged between twenty one to sixty three. Most of the parents were educated and were residing as a couple. Majority of the females were housewives and living in a nuclear families. Sixty five children were between five to twenty eight years. Maximum numbers of intellectually disabled children were the first born and majority of them were not going to school. Result of the study showed that parents reported more positive impact having children with intellectual disability. Parents had developed more persistence, acceptance, empathy and also higher understanding between the partners. It also reported to have a great information of resources around, Apart from this their knowledge, training about behavior intervention techniques, schemes, benefits run by government had increased greatly. The study also highlighted some negative impact including difficulties in meeting extra burden with physical care of the child, experiencing health related issues, making career adjustments, loss of support from the partner and meeting extra demands with physical care of the child. This study also showed that it is not necessary that every family of retarded children
will have negative impact. In some families this problem can generate a positive impact like acceptance of the situation in a practical manner and provide every possible support to the children, more understanding between partners.

Gupta and Kaur. (2010) in their research on” Stress among parents of children with intellectual disability” took one hundred and two parents, thirty of whom had children without disability. T test was applied to test differences in stress, gender difference and difference in mental and physical stress. Three schools meant for children with intellectual disability were chosen. These schools were from Chandigarh, Jalandhar and Ludhiana in India. Three schools for regular children in age group of nine to fifteen from Patiala were taken on convenient sampling basis. Thirty parents had children with no disability, sixty five parents had children with intellectual disability, seven couples filled the questionnaire together, and hence those data had to be dropped. Results indicated that most subjects showed higher mental stress than physical stress. Most parents of children with intellectual disability experience stress. Physical and mental stress was found to be significantly correlated. Gender differences in stress were observed in the mental area. Overall parents had higher mental stress score as compared to physical stress.

Lakhan and Sharma (2010) in their study on “A study of knowledge, attitudes and practices (KAP): Survey of families toward their children with intellectual disability in Barwani, India”. conducted an assessment through interviews of knowledge, attitudes and practices related to intellectual disability among families. For this purpose total of forty one parents (tribal-twenty eight & non-tribal -thirteen) from forty three villages with children in age group of ten to fifteen years were taken. The objectives of the study were to understand knowledge, attitudes and practices of families towards their children with intellectual disability and to prepare suitable awareness material and project a strategy for a community based rehabilitation project. Two blocks of Barwani district were selected for this study. Statistically significant difference was found between two groups largely on six themes: disability occurs due to sin, faith healing can cure, the child can benefit from the school, can be trained to speak, have disability certificate and involve in household activities. Majority of tribal parents believed that their children became disabled due to their sin or previous birth. Large number of parents in both tribal and non- tribal believed that people with intellectual disability cannot manage their lives independently. Some were also of the view that person with disability cannot marry. Results showed that
both groups (tribal and non-tribal) are either had lack of information or do not receive suitable services from anywhere. They even had misconceptions and misperceptions related to their child’s disability. Another major dimension observed was that tribal families involve their children more and do not show much discrimination while the non-tribal group restricts participation of their children in day to day life. Parents were convinced that their offspring could be cured if they can remove the effects of God’s punishment by prayers. They paid money to faith healers, used practices like beating, burning their stomach and not giving food for days in the name of treatment. According to many tribal parents the community believed that the intellectual disability was contagious, and could infect other children. This study revealed that there is lack of awareness in the community at large regarding intellectual disability. Apart from this tribal parents showed more humanitarian approach in handling behavioral problems while non-tribal seemed to be demanding and pushy for desired behavior. The study suggested that attempts should be made to build awareness among parents on various aspects of mental disability ranging from their handling at home, education and rehabilitation at large.

Prashant Jahuhari et al. (2012) in a study on “Co-morbidities associated with intellectual disability among paediatric outpatients seen at a teaching hospital in northern India”. highlighted the occurrence of common co morbidities in children who have intellectual disability. This study was conducted at one of the medical university in Lucknow, India. The sample was taken from the children who were between the age of 6 months and 15 years however the median age of the child was 30 months. Sample was taken from the children who have either developmental or language delays or suspected intellectual disability. All the children had to undergo Psychometric test by child psychologist. Results showed that there were high rate of associated disability in children along with intellectual disability, which lead to various other problems. Epilepsy was more commonly found among the children with intellectual disability followed by hearing and vision problems. These co morbidities were found among children who had moderate to severe intellectual disability. It was also noted that behavioural problems was main co morbid condition among children with intellectual disability. Interestingly, autism and attention deficit hyperactive disorder were found in very few children. This research threw a light on the issues that child with an intellectual disability who had more associated co morbid conditions, leads to lot of stress among caregivers. This study also suggested that
these children would benefit from availability of multidisciplinary team such as occupational therapist, speech therapist and special educators etc however in less developed countries this multidisciplinary team does not exist.

Aesha Farheen et al. (2013) in a study “Stress perceived by families with mentally retarded children enrolled in special schools at Indore”. found various types of stress families faces having a child with disability in the family. In this study 100 families with 102 children with intellectual disability enrolled in a special school were taken. To get the results family assessment schedule was developed for family interview followed by semi structured interview. Results showed that families having a child with disability undergo numerous stresses. Families reported emotional stress, daily care stress and financial stress however it was interesting to know that no family reported threat to marital relationship.

Sahay Amrita et.al (2013) in their study on ‘Parents of Intellectually Disabled Children: A Study of Their Needs and Expectations’ premeditated to examine the needs of parents under seven domains such as family, social and professional support, information and financial needs, childcare, community services and explaining to others. The result of the study revealed that most of the parents put forth the need for information and financial support, parents also talked of the needs of childcare, community services and professional support and a small percentage of parents expressed the need of family and social support. The parents need information about the child’s disability for handling child behavior. Most of parents didn't want to disclose any information about child though they preferred the need for information about future and current service available in society and the community, a need for ongoing, up-to-date information throughout the continuum of care, particularly in the technology development.

Sridevi Godishala & M.S. Kerenhappachu (2014)“Care givers burden and perceived social support in mothers of children with mental retardation”. The sample of the study included mothers of children with mental retardation with the mothers of normal children. The sample consisted of thirty mother each with children in the age group of three to fifteen years. The results showed significant differences in the areas of emotional involvement social support, disappointment and general strain. The mothers of children with mental retardation experienced significantly higher burden and also opted for more social support.
Rajib Bhattacharaya (2014) in his research work on the study of “Disability Laws in India: A study”. highlighted the concept of disability and emphasized a range of legal provisions and laws available in India and how these laws plays an important role to empower persons with disability in India. Disability is understood differently by different people in all societies. Persons with disability are considered inferior or unfair for the society and are thus discriminated by them. People see them as an object of charity however with enactment of various laws and after signing a proclamation on full participation and equality of people with disability in Asian – Pacific region ensure that persons with disability have equal rights in the society as others. According to article 15 of the constitution of India, no one can discriminate persons with disability on the basis of colour, sex or caste and every person with disability has a right to access any public place. Law further states that persons with a disability have a right to opt any religion they want and like other persons they have a right to vote when they became an adult. Furthermore, they have right of education like every person. Article 45 of the constitution states that state has to provide free and compulsory education and children with disability have a right get to free books and are entitled to scholarships. Above all there is a reservation in employment for people with disability and there is a provision of unemployment allowance to the persons with disability who are registered with special employment exchange. Even the health laws of India have many provisions for persons with disability. Apart from this, according to Hindu Succession Act, no person with disability can be deprived from inheriting an ancestral property. The other provisions are the concession in income tax, education, employment and rehabilitation for persons with disability. According to Mental Health Act 1987, mentally ill persons have a right to be admitted or treated in a psychiatric hospital or nursing home and at the same time they have a right to be discharged when cured. Also, persons with mental illness are entitled to get allowances from the government. The Rehabilitation council of India 1992 states that person with disability have right to be served by trained and qualified rehabilitation professionals. Above all the National trust for welfare of persons of Autism, cerebral palsy, mental retardation and multiple disability act 1999 and judiciary also plays significant role in protecting human rights of disabled persons.
2.2 Studies Conducted Abroad

Jani (1967) in a study on “Mentally retarded child in family” examined the social issues related to the occurrence of a child with intellectual disability. Results of the study indicated that parental feelings were marked by worry about future. Certain other significant facts observed were psychological strain among siblings, decreased interaction with neighbours and relatives, misunderstandings within the family and economic defeat, which meant limited resources for each child.

Gath (1978) compared two groups of families, those with a down syndrome child and normal child of the same age in the same home. Both were studied from the time of their birth. It was found that among the parents of the young children with Down’s syndrome, a significant percentage gave indication of marital discord. However others felt that their bond had been strengthened by looking after the birth of child with a disability and also concluded that most of the families have adjusted well by accepting their child’s disability. However siblings were at some disadvantage because of the time and effort that had to be committed to the child with a disability.

Florian and Shurka (1981) in their research on "Jewish and Arab parents coping with their disabled child in Israel" found that Arabs have conventional family structures in which great meaning was attached to shame, honor and self-esteem. Parents of children with disabilities in Arab cultures mostly kept their children at home, restraining their opportunities for inclusion in community activities. They also preferred to make widespread use of informal support from the extended family.

Kazak and Marvin (1984) in their paper “Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child” stated that families of children with a disability act in response to increased stress in a variety of ways. Some parents may identify positive outcomes from caring of their child with disability, which may be a significant coping device. While some families may also adopt avoidance-coping strategies and self blame as their responses.

Hurh & Kim (1988) undertook a comparative study in America and Korea on “Uprooting and adjustment: A sociological study of Korean immigrants’ mental health” Where they found that apart from different cultural orientation, families in both countries are also different in their help-seeking behaviour. In a socialist culture such as Korea, when members of a family face problems such as financial or health of their child, prefer to depend on their family for problem-solving instead of looking for outside source of help. The same principle applies to Korean mothers of children even
with mental retardation. They also prefer to depend upon their family members to help them to take care of their child with disability. American mothers are more likely to rely on professionals.

Saifer et al. (1992) in their empirical finding on “Child and family factors that ameliorate risk between four and thirteen years of age” found that the family stressors related with inadequate financial possessions, lack of suitable services, and inadequate support systems are examples of family system risk factors. Environmental risk factors such as lack of services and negative approach may also have an adverse effect on the prognosis of the child with autism. Various studies have been done to understand negative aspects and stress faced by the parents of children with disabilities however Behr, Murphy and Summers (1992) while discussing “Users manual: Kansas inventory of parental perceptions (KIPP)” highlighted positive perceptions in parents of children with disabilities. They conducted a study on more than twelve hundred families and identified some encouraging factors of having a child with disability. These included: source of happiness and love, contribution to family strength, motivation to parents for their personal growth and development, source of pride, gives way to learn, key to understand life’s purpose, a guide to understand future issues and, a motivation for career growth.

Gray (1993) in his article on “Perceptions of stigma: The parents of autistic children” described various dimensions of perceiving stigma. The study put forth that almost all parents of children with autism felt highly stigmatized in community situations as compared to the parents of more severely disabled children. This mainly happened due to exceptionally disruptive nature of autistic signs such as difficulty in social communications, lack of public awareness and knowledge about autism. Some important factors linked with parental strain in families of children with autism also included, feeling of failure of individual control, absence of spousal support, informal and professional support, adjustments to the reality of the child’s state, housing and finance. In the case of families with destructive and aggressive children and minimum resources to handle or residential placement to deal with their condition, the parents experienced high level of pressure. It has also been found that mother’s being the primary caregiver, cater to their child’s everyday needs such as shopping, recreation thus experience more stigma.

Stainton and Beaser (1998) carried out the study “Positive impact on parents having disabled children” reported that parents having children with intellectual
disability also have some positive impact. Parents realized that their personal and social networks have prolonged and children have now become their source of pleasure, family unity and closeness. Parent’s acceptance and understanding have also increased. They are now able to link to the community activities more.

Krauss and Seltzer (1999) described in their study on “An unanticipated life: The impact of lifelong care giving, in responding to the challenge: Current trends and international issues in developmental disabilities.” It said that the upbringing of child with disability is influenced by the culture in which he lives. Presence of a child with intellectual disability in Arab culture may be highly stigmatized especially for mothers. However, it was also found that with proper support, families could find positive ways to deal with the stress they face. The parents could build up the bonds between one another and discover new paths of communication and affection that did not exist in their relationship before.

Scorgie et al. (1999) research “Transforming partnerships: Parent life management issues when a child has mental retardation” revealed that parents arrived at a more positive condition through three processes. Firstly need to form new identities, then attempts to obtain meaning from the situation and lastly development of a sense of personal control. Wherein some parents reported failure of friendships, a result of having a child with disability. Though some stated that they have formed good relationships with personnel from agencies working for people with disabilities and even health care professionals have become an important part of their friendship network. Whereas some parents also reported that they might not have had interaction with any one in such a depth if they had not had a child with a disability.

Marika (1999) gave significant contribution in her study on “Depression symptoms and emotional stress in parents of disabled and non-disabled children”. The study sample consisted of one hundred fifty one mothers and fifty seven fathers of disabled children and one hundred one mothers and fifty five fathers of non-disabled children. The results showed that parents, especially mothers of children with disability had significantly more negative emotional state and had more depressive symptoms. Significant differences in depression symptoms between the disabled and controlled parent group were found in most symptoms. Parents in the controlled group were significantly more happy, satisfied, proud, and grateful for their child whereas parents of disabled children were more under strain, and concerned about their child’s future. Though some parents at times even felt exhausted, desperate and vulnerable.
The mothers of children with disability had higher scores in pessimistic emotional states than fathers.

Baxter et al. (2000) in article on “Parental stress attributed to family members with and without disability” found that the stress experienced by families who have a child with disability was double than that experienced by families whose child did not have a disability. Mothers of children with intellectual disability were likely to be more affected by stress than fathers.

Durvasula and Beange (2001) in their finding on “Health inequalities in people with intellectual disability: Strategies for improvement.” paid attention on the health disadvantages faced by people with intellectual disability. The barriers to health care access and strategies to deal with the primary health requirements of this population were reviewed. Australian Bureau of Statistics showed 7.2% of people with intellectual or developmental delay are in institutions, nursing homes or hostels. The rest live either independently, with their families, in supported accommodation or in the community at large. This population therefore relies on mainstream primary and preventive health services. Although the life expectancy of people with intellectual disability has improved in the last thirty years, it is still considerably less than that of the general population. It was observed that people with intellectual disability face many health complications as other normal people in the community faces such as hearing loss, epilepsy, thyroid diseases, dental problems, obesity and even cancer. Apart from this, people with intellectual disability can not access health promotion activities due to many barriers to health care access which included socioeconomic disadvantage, lack of knowledge of health problems, negative attitudes, poor communication abilities and poor partnership between services. Many of them faced above problems because they were likely to be socially and economically deprived and majority of them depend on government income support. Those who are employed tend to work in low paid jobs, which are often part time or casual in nature. Australian survey of general practitioner and general practice trainees had shown that the majority of general practitioners believed that they lack knowledge and confidence when dealing with patients with intellectual disability. Another barrier was negative attitudes of carers regarding paying special attention to health issues of person with disabilities which according to them bring stigma and labels disability among that person. Above all, the other contributing factor was that a high percentage of people with intellectual disability have limited communication
abilities, making it hard for them to describe symptoms. Other obstruction is, when person with intellectual disability has a dual diagnosis. If a person has a mental health issues then the responsibility is of mental health sector or if the person has behavior problems then the responsibility is of disability sector. In some instances the individual receives no support from either sector. In spite of all these barriers, a variety of strategies have been recommended to conquer these barriers such as providing education and training to health care personnel about the important health issues. Education also needs to be provided to carers, family members and individuals with intellectual disability. Some small scale health promotion programs had been developed particularly for people with intellectual disability and have had some success. Health promotion programmes can be useful in this population. Regular and complete health reviews for people with intellectual disability had been recommended by many researchers. Above all, it is equally important to acknowledge that people with intellectual disability have the same right to good health and excellence in health care as others in the community. Lastly readiness of the health and disability sectors to work together to accomplish positive health outcomes and improve the quality of life for people with intellectual disability is also important.

Jin (2002) had done research on “Social support for families with mental retardation: Comparison between Korea and the United States” where they undertook a comparative study on familial and professionals supports available to families of children with mental retardation. Apart from this, the effects of cultural and social support on maternal pressure were also measured. Thirty eight American and forty Korean mothers participated in the home visit discussion. Results showed that American mothers received more informal and professional support in almost all domains of social support whereas Korean mothers faced more pressure. In this study researcher paid attention on particular types of informal and formal support available to families of children with mental retardation from two specifically unlike countries—Korea and United States. Researcher paid attention on particular types of informal and formal support available to families in both countries. A total of three hundred and seven mothers who had a child with mental retardation were recruited from elementary schools in two metropolitan areas in the United States and Korea, seventy eight mothers (thirty eight American and forty Korean) participated and fulfilled the interview. The participating mothers ranged in age group of thirty one to fifty years. The majority of American mothers were married though some were divorced too.
High school completion was the highest education. High school graduation was the highest educational level for Korean mothers. Though the American mothers had considerably more education than Korean mothers but there was no considerable difference in education between American and Korean fathers. Results showed, where availability of informal support was concerned, there was no significant difference between the two groups, with the exception of friends and sources of professional support. American mothers had more friends and professional support available to them than Korean mothers. The two groups of mothers used some services at a comparable level, but with different purposes. American mothers utilized services of private therapists, mostly speech therapists. School therapists, speech pathologists and other professionals were taken for granted by American mothers, but rarely by Korean mothers. In Korea many professional services such as speech therapy were not available at the regular school. Korean mothers however were more likely to hire tutors who worked with their children on educational resources. When both groups of mothers were compared on the stress measure, Korean mothers reported higher stress than American mothers. The Korean mothers appeared to be doubly trapped because of the society’s negative attitudes toward disabilities. This stopped them from being open about their children which included sharing of experiences with people around them and the lack of social support network associated with the society’s mobility.

Turmusani (2003) described in his study on “Disabled people and economic needs in the developing world” conducted in UAE stated that religious attitude may control parents’ ability to cope with their child’s disability. Even some interpretations of the Islamic religion see disability as a reprimand from God resulting from a committed sin, or uninformed penalty of divine will.

Salovita et al. (2003) in their investigation on “Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model.” The double ABCX model,(aA) consisted of various stressors and strain (bB) factor contained existing family resources for meeting the demands and their necessities (cC) consisting of the meaning the family assigns to their situation, family crisis and post-crisis adjustment (xX) is the outcome factor. The aim of this study was to forecast the adjustment of fathers and mothers while giving care to a child with an intellectual disability using the mechanism of the double ABCX model of family adjustment. Data was gathered through a questionnaire which consisted of three different forms, each to be answered by mother, father and one by both together. A
total of six hundred forty seven families i.e. fifty eight percent of the sample answered at least one part of the questionnaire. To measure the (aA) factor, age of the child, adaptive skills, challenging behavior and level of disability were taken into account. Family adaptive resource (bB) was measured by using Marital Adjustment Test of Locke and Wallace. Various scales such as personal assessment of intimacy in relationships, likert scale, and family support scale to measure support obtained from the spouse or by the parents were also used. The meaning that the parents gave to their situation (cC) was measured by the Social Readjustment Rating Scale. Results showed that the original stressor variables, i.e. the personality of the child (aA factor) predicted two percent of the stress of mothers and eight percent of the stress of fathers. On the other hand family resource (bB) factor accounted for forty percent of the stress of mothers and thirty three percent of fathers, whereas the family definition of the situation (cC) factor explained twenty nine percent of the stress among mothers and thirty seven percent among fathers. These results proved the importance of intervening factors to explain the stress among parents who have a child with intellectual disability, family resources and spousal support were considered to be an important factor to alleviate some of their stress. The study also said that the families who have been able to reframe their child’s disability in an optimistic way or took as a routine factor of their daily life did not experience high levels of stress.

Gray (2003) gave a significant contribution in his study on “Gender and coping: The parents of children with high functioning autism”. It showed that mothers had a considerable effect on their emotional well being and also on their careers. Mothers, who managed to work, were often forced to miss work and switch to part time work. It was also found that for some mothers, this was the cause of anger. Whereas for fathers, most serious effect of their child’s autism was the stress experienced by their wives. Fathers felt that their sacrifice was in having to work harder to support the extra demands on the family, as a result of the child’s disability.

Brett (2004) identified “The Journey to accepting support: How parents of profoundly disabled children experience support in their lives” In-depth interviews with six parents randomly selected from a purposive sample in a special school setting was conducted. The themes were: parents’ feelings about support, their journey towards accepting support, support as a loss, disability and the parent, their cooperative relationship. Here the parents were asked to take a small number of moments to focus upon the experience of support in their life, times of particular
awareness, impact that support may have had and then explain the experience as fully as possible. Interviews were recorded and transcribed. Parents spoke of contradictory and perplexing emotions regarding this point in their lives where they recognized the need for support. They also felt that at the point when they recognized the need for support, they felt that world had broken down in some way. The disturbance of everyday activity had a direct link with the point at which parents admit the need for support in their lives. Following the processes of recognizing and acknowledging their need for support, parents expressed concerns about asking for and accepting support. They felt that asking for support was an admission of failure. Some even viewed it as a form of loss. Apart from this another considerable observation was that the expectations of parenthood by professionals and society could be a powerful combination, which may make parents feel that they are failing. While this study explored the experience of parents of profoundly disabled children as they travel a journey to accept support in their lives, suggested that understanding experience of support from the parents’ perspective may lead to a consideration of flexible systems that challenge practice to ensure that supporters listens, develop and convey support in ways that are actually useful.

Hastings and Alexandra (2004) conducted study on “Stress intervention for parents of children with intellectual disabilities” and found that parents of children with intellectual disabilities are at high risk for stress and other mental health problems. The purpose of the study was to review and consider importance of psychological intervention to alleviate stress in the parents. A selective review of interventions were planned to lessen stress in parents of children with intellectual disabilities, with a focus on group interventions that include various cognitive behavioral techniques. Family researchers in the field of intellectual disabilities often assessed the relationships between formal service, professional support and parental well being. This study involved one hundred twenty eight parents who responded to advertisements for the service in the five states in the USA. No parents were excluded from the service, but those needing urgent help were not included in the evaluation study. The parent to parent model was designed by parents themselves, where the parent who had been caring for a child with disability got some training in support techniques and parent seeking support was matched with a parent supporter as closely as possible. Results showed that parent model proved to be very helpful for the parents as they found that everyone had a similar situation however talking with each
other about the situation helped to alleviate some stress. Apart from this respite care and case management helped to reduce stress among parents to a large extent. It was also found that group interventions proved to be very useful especially to reduce stress among mothers.

Green et al. (2005) conducted a study on “Living stigma: The impact of labeling, stereotyping, separation, status loss and discrimination in the lives of individuals with disabilities and their families.” This study examined the direct impact of the social processes, attached disgrace and their impact on the lives of the individuals with disability and their families. The sample covered seven mothers whose children had been diagnosed with a variety of impairments and disabilities including cerebral palsy, down syndrome, severe autism and specific developmental delay. At the time of interview, their children ranged in age from preschoolers to high school. Six mothers were still married to the child’s father whereas one was a single mother. Result suggested that people with disabilities are generally perceived to acquire traits that others do not want to attain. Thus they may experience unhappiness in the presence of persons with disabilities. These emotions can further interfere in the process of social interaction. Views of separated mothers included the affect of labeling and stereotyping on their lives. It was found that separation at times occurs when the reactions of others create a sense of being devalued and insulted. Blame was also a powerful source of social separation. The mothers who participated in the study reported that they sometimes feel answerable for their child’s differences. Another considerable indication of this study was that these individuals find varied and creative ways to resist and actively counter the negative effects of stigma in their lives. Overall the findings support the difficulty of the experience of stigma and the importance of the socio-cultural context to the lived experience of disability.

Mathilde et al. (2006) in their article on “The adaptation of mothers of children with intellectual disability in Lebanon” found that in many Middle Eastern countries as well as Lebanon there is shame attached to families who have an intellectually disabled child. These families complain of loneliness and lack of community resources that could help them to cope with their situations to optimize the child’s abilities. The aim of this cross-sectional study was to identify factors that play a role in mother’s adjustment in the care of their intellectually disabled children. The samples of one hundred twenty seven mothers from Lebanon were taken and results showed that being the sole carer of the child with disability, high percentage of
mothers suffered from depression. For data analysis (SPSS) Statistical Package for the Social Sciences was used. Results of this study also showed that Lebanese families of children with intellectual disability have a reasonable level of family strain. This strain often arose from intra family and financial strains placed on the family when caring for an intellectually disabled child. The families with high income and medical insurance had lower strain and better coping resources. Furthermore high maternal education level was associated with lower family strain. It is also noted that Lebanese society is not yet well prepared to offer help to families who have children with developmental delays. Most mothers choose to isolate themselves and keep their child at home to avoid stigmatization and criticism. Many studies found that social support and coping resources have affect on how the family experiences the disability and can even lessen the pressure resulting from it. Sources of stress were related to the nature, severity of the disability and their significance for the family members. According to a previous study by ministry of public health, (2001) children in Lebanon, with intellectual disability represented twenty five percent of the population with particular requirements. The four standardized instruments were used to gather a data at that time and depressive symptoms were used as an indicator of psychological stress. Family tension, pressure and coping were assessed by using these scales.

Fidler et al. (2006) reported in their study on “Stress trajectories in families of young children with down syndrome”. It said that pressure among parents of children with Down syndrome amplified over the first three years of life. It seemed to be tied to the child’s greater cognitive, linguistic deficits and maladaptive behaviors. Prevalence of early divorces could also be linked to the high rates and severity of medical issues in children with Down syndrome, mostly during the earliest years.

Singer (2006) found that many families of children with developmental disability are at threat of having higher levels of strain in contrast to families of normally developing children. The problem focused coping factor addressed the use of social support and planned problem solving skills. The emotion focused coping part addressed coping strategies such as unfriendliness, accepting responsibility and positive reassessment. Results of this study showed that there was a considerable relationship between emotion focused coping and family adaptation, indicating that parents who used emotional focused coping have better adaptation levels. Differences between mean scales scores of mothers and fathers on family adaptation, parenting
contentment, problem focused coping and emotional focused coping were not statistically significant.

Edwards and Higgins et al. (2007) in their note on “The families caring for a person with a disability and the social lives of carers” explored how the lives of carers were affected by looking after a person with a disability. In this study a random sample of five thousand carers who were receiving carer payment was selected from centre link records. However one hundred two carers were interviewed via telephone. Results showed that friend circle of carers was unaffected and a small minority even indicated that their circle of friends had enlarged as a result of caring a person with the disability. Almost one quarter of carers indicated that they had lost or were losing touch with existing friends since they had started caring. They also indicated that they had less time to spend with family members since they began caring. They had lower face to face social contacts than others who were not having caring responsibilities for a person with disability. It was also found that the experience of financial hardship could limit the ability of carers to see friends or relatives outside of the household. As this could effect the costs of either catering for visitors or the cost of going out in general. Carers of a person with a disability with high care needs were almost twice than carers of a person with the low care needs. According to Australian Bureau of Statistics (2003) thirteen percent of people living in households in Australia were carers who provided some support to those who wanted help because of disability or their age.

Murray (2007) conducted a study on “Families care of their children with severe disabilities in Australia” based on depth interviews with parents of children with disabilities who need the support services most and identified the area that need more attention. The study highlighted the parental issues related to income, work, leisure and social relationships. The interviews were semi structured and were conducted at a time and place suitable to the participants. Eight families were interviewed, out of them, five lived in Melbourne and three lived in rural Victoria in a regional centre or town. There were a total of twenty one children in these eight families, eleven of whom as identified by their parents were having severe or profound disabilities. The age of these children ranged between four to sixteen years. Two of the families had more than one child with severe disabilities. Seven of the primary carers were women and six of the families were nuclear, one was single parent family. All families received some form of income support at the time of
interview and some were those in receipt of carer’s payment, disability support pension and parenting payment. Some participants also received additional forms of financial support such as concession card and pharmaceutical allowance. Whereas other families of children with disabilities found it difficult to participate in paid work, as fitting a job around caring responsibilities is difficult. All participants in this study expressed a wish to work but were upset by a series of factors including their own ill health, unsuitability of after school care and holiday care amenities and irregular demands of care such as responding to their child’s ill health and not having leave to cover or not feeling comfortable to ask for leave. Families described their commitment in leisure activities both in terms of further care work and as opportunities to have time, free from care when alternative care was presented for their children. The demands of care and limited amounts of alternative care often left the families with little time to engage in any form of leisure activities. They were not be able to access some of the community services such as child care, play and relaxation. It was also found that these families to a great extent, felt the loss of friends and changed their social network. Many families commented on the insufficiency of support to families and difficulties in accessing and managing assistance. Communication between support agencies and professionals was also perceived as a problem. Much time was taken up providing and maintaining information. The study concluded that existing support services have not enabled families yet to be a part of the wider community.

Bayat (2007) in an article “Evidence of resilience in families of children with autism” stated that although parents commonly focus on bringing out positive meaning from their experiences. Still caring for a child with disability can be a psychologically, economically and individually demanding experience. Results suggested identification of specific resilience processes, such as: making positive meaning out of disability, mobilization of resources, becoming united and closer as a family, finding greater appreciation of life in general, and other people in specific, and also gaining spiritual strength.

Reichman et al. (2007) took a comprehensive view on “Impact of child’s disability on the family” where they found the complex needs and multitude of resources available to families of children with disability and also gave some suggestions. It says residing with a child who has disability had intense effects on the entire family, whether is the parents, siblings or extended family. The time, economic
costs, physical and emotional demands connected with raising a disabled child could have far reaching effects on the family. For parents, with such a child these could be increased pressure of poor physical and mental health or while facing difficulty in finding suitable and reasonable child care. Above all it could affect choice about work and relying on public support. At times parents even have feelings of guilt, shame, blame and reduced self respect. Another negative aspect is that, while trying to address the simple needs of their disabled children, parents have to interact in variety of public and private institutions, where at times there is not a single source of information on the resources available for children with disability. For each programme parents need to be aware of its existence and at times have to wait months or years to be offered services. However on the positive note it can broaden parent’s horizons, increase family members awareness of their inner strength, increase family cohesion and also link them to local support groups or religious institutions. Researcher in this study found that the most important need of the parents is finding the resources. Children with a disability do not only need good primary care, but they frequently require multi dimensional specialized care on long term basis. Apart from health care need, academic, recreation and social needs are some significant ones. For some parents it becomes a problem when the child has mobility issues, specifically ones who reside in poor or inner city areas and depend on public transportation. However for such families of disabled children, there are some programs and organizations that provide resources. Medical care can be financed by private insurance companies. Resources that help family members directly include respite care, counseling, parent and sibling groups as well as national clearing houses for providing information about available resources. The clinician also play an important role in informing parents about the range of services and some bitter truths about the system, which are extremely difficult to navigate.

Urbano et al. (2007) conducted a study on “Divorce in families of children with down syndrome”. The nature, timing and correlates of divorce in families of children with down syndrome, other birth defects and no identified disability were examined. It was found that divorce rates among families of children with down syndrome were lower than in the other two groups where there are other birth defects and no identified disability. Divorce did occur in the down syndrome group, however a high percentage occurred within the first two years following the child’s birth. This study featured three main findings. The first concerned the occurrence of divorce
among parents of children with down syndrome. These parents were slightly less likely to divorce than were parents of children without disabilities or with other birth defects whereas in earlier studies of disabilities in general, including the few, researches done on big scale found opposite pattern. Here divorce occurred proportionally more often among parents of children with disabilities. Another issue that came up was parent characteristics of low levels of education and rural conditions. Although more divorce occurred among less educated parents in all groups but parents of children with Down syndrome were more likely to divorce when either the mother or the father did not have a high school education. Similarly, families in which fathers had not graduated high school seemed predominantly at risk for parental divorcé. Another issue that came up was that the presence of boys had been shown to minimize the possibility of parental divorce.

Mark et al. (2008) carried out study to investigate “Affiliate stigma, caregivers of people with intellectual disability or mental illness”. It had two hundred and ten caregivers of people with intellectual disability and one hundred eight caregivers of people with mental illness. They were taken to authenticate twenty two items of affiliate stigma scale with care giving pressure, burden and positive perceptions. Stigma affects not only the public but also individuals who are connected with the targeted individuals like family members, caregivers, friends and service providers. As a result they may be individually affected, feel unhappy and dependent about their attachment with the stigmatized individual and recognize a negative influence on themselves. The issue of affiliated stigma is particularly significant among Chinese people because of their cultural attitude towards mental illness and intellectual disability. Research has found that Chinese people at times believe their child as a ‘bad seed’ and a dishonor to their family. They are likely to keep their child’s disability, a family secret to avoid face loss. In the care giving context caregivers with affiliate stigma may perceive great sense of trouble and strain in care giving because stigma at times distorts their views towards their care recipients and affect their relationships. In this study the participant mothers age ranged between twenty four to fifty eight, whose children had a mild level of intellectual disability and close to half of them had an additional diagnosis of autism. A majority of the mothers had high school education and were not employed. Structured questionnaires and interview method adopted twenty two scale item. This scale was developed to gauge caregivers internalization of stigma. A measure of daily care giving pressure was developed by
Hastings et al. in measuring fifteen care domains including dressing, toileting, calming when upset, feeding, giving medication, sleep, shopping, visiting friends, going out, doing enjoyable things, lifting, physically handling, caring and others attachment. Daily care giving stress was measured by the chronic stressors scale. Caregivers’ positive perceptions were measured by four scales of the kansas inventory of parental perceptions including source of happiness and fulfillment, source of strength and family closeness. Results showed that associated stigma is a significant subject of concern among caregivers. Caregivers with high levels of affiliate stigma were likely to have a sense of shame and weakness as a result of their connection with the affected individuals. In addition to this, kinship plays a significant role in social support, caregivers, restricted disclosure to the extended family would potentially lead to the loss of social support, increased stress and affiliate stigma. In addition to integrating discussion of stigma into psycho educational programmes, sharing stigma experience in mutual support groups care givers of people with intellectual disability(CPID) and care givers of people with mental illness(CPMI) may be beneficial for their overall well being. Through mutual support such actions may empower caregivers and lessen isolation, which may play a critical role in reduction of stigma and improvement of their own mental health. The present study is one of the first attempts to conceptualize stigma from the perspective of the associates and to build up a quantitative measure of affiliate stigma to understand its relationships with the care giving experience.

Mayes et al. (2008) in a article on “ Active negotiation: Mothers with intellectual disabilities creating their social support networks” confirmed that a considerable factors influencing overall family performance and how well parents manage depends upon the support, acquaintance and guidance they get from their familiar support networks, particularly close friends and extended family such as grandparents.

Bostrom et al. (2009) did a study on “Parents’ descriptions and experiences of young children with intellectual disability”. The aim of the study was to investigate the difference of parents’ descriptions and experiences of their child that was recently recognized to have an intellectual disability. Data was collected from nine fathers and eight mothers through semi-structured interviews within six months subsequent to diagnosis. In the study seventeen parents were taken whose children were aged between five months to five years. All parents were co-habiting or a married, natural
parent of the child at the time of an interview. The aim of the interview was to attain an image of parents’ perceptions and subjective experiences. Each interview was audio taped and later the verbatim was transcribed. Results showed that most of the parents provided rich and varied descriptions of the child and were considered to be balanced despite the high occurrence of negative descriptions. It was seen that images and opportunity of the child and parenthood are formed and developed to a varying degree by the parents prior to the birth of the child. Getting a diagnosis was considered to be experienced as a loss or shock by parents and affected parental representations of the child. Some parents appeared to be struggling with thoughts about the diagnosis and experienced the disability as a central element in their everyday lives causing negative emotions. Some parents had already arrived at an acceptance of the disability. Generally parents of children with intellectual disability described negative emotions in relation to the child and the disability, whereas some parents felt positive emotions that seemed to balance the negative experiences.

Tsai and Wang (2009) in a study on “The relationship between caregiver’s strain and social support among others with intellectually disabled children” aimed to check out caregiver’s strain, the relationship between social support and caregivers’ strain and the predictors of caregiver’s strain among mothers with school-aged intellectually disabled children in Taiwan. Data was collected from one hundred twenty seven mothers. The inclusion criteria for the participation of mothers were the ones who had a seven to twelve year old intellectually disabled children who were able to communicate in either Mandarin or Taiwanese. The socio demographic inventory was developed. Mothers’ strain was measured by caregiver strain index and social support scale developed by Tang to measure social support. Results showed that the parents of intellectually disabled children received more support from informal sources i.e. family, friends or spouses. Out of which the support of the spouse within the family was considered most important support. Social support is usually classified into four types, emotional support from relatives or friends who provide positive expressions of emotions, informational support from relatives or close friends who provides relevant knowledge and information, instrumental support from relatives or close friends who provide materialistic and financial support and appraisal support that boosts an individual’s self esteem also provides recognition or praise. Findings also showed that mothers’ health status had a negative correlation with strain. Amount of time spent as a caregiver had a positive correlation with strain.
Mothers who spent a longer time as a caregiver perceived a higher level of strain. It was also discovered that these mothers were facing difficulty in making decisions regarding choice of school, method of education and rehabilitation courses. In case of a girl child they were more worried about her safety and future. To some extent social support played an important role in reducing the strain experienced by them. However there are few formal resources to support these mothers. This study also found that support for the mothers was provided by the spouse whereas experience sharing and advice from other mothers with an intellectually disabled child was also significant. Apart from this mothers reported that social workers, physicians’ nurses had not provided adequate information and assistance to them. In Taiwan professionals were rarely involved in self help groups, mothers are only able to share their experiences with each other. Support of professionals can play an active role by helping to organize intellectually disabled children’s support groups.

Gill and Liamputtong (2009) in their paper on “Walk a mile in my shoes: Researching the lived experiences of mothers of children with autism.” explored the experience of mothers who had a child with autism. This study aimed to give voice to them by providing them with the opportunity to do so by means of methods tailored to their circumstances. The major objectives of this study were to explore the meaning of motherhood among mothers of children with autism, their perceptions of an ideal motherhood. It also, explored how they perceive themselves, their experiences, feelings and how they cope with their role as a mother. Researcher found that due to complexity of the disability, the process of obtaining accurate diagnosis and treatment is often long and thus causes frustration among the parents. The lack of known cause for the disability also brings up issues of self-blame more among mothers themselves than fathers. Various studies done in the past showed that mothers suffer more physical and emotional stress than fathers when dealing with their autistic child as they are the primary caregiver and therefore they had to deal with more stigma within the community. In this study researcher utilized in-depth interviews to explore the experiences of mothers with autistic children. The diary method was also incorporated where every participant was interviewed twice before and after the diary was written. In-depth interviews helped to discover the subjective meanings and interpretations that people give to their experiences. The participants involved in the interview found the experience to be very rewarding since it gave them a chance to share their stories and gain more insight. The diary method helped the researchers to have deep
understanding of experiences of dealing with daily discrimination and caring for a child with disability. It also offered valuable insight into the often hidden aspects of the individual's life and facilitate collection of data on sensitive issues. Another benefit of this method was that participants were able to write whatever suited them at whatever time. They could report their day to day experiences and researcher could further investigate those experiences in subsequent interviews. The respondents were asked to keep a diary record for one week and latter it was used for an in-depth discussion to review the individual experiences of motherhood of the participants. This method also helped to build a strong relationship between participant and researcher. Which further led to qualitative approach, clear understanding of the perceptions and experiences of motherhood of autistic children. Thus helped to generate better understanding and empathy for those affected or involved with the disability.

Dukmak (2009) in an article on “Parent's adaptation to the parenting satisfaction of children with intellectual disability in the United Arab Emirates” investigated the impact that children with intellectual disability may have on their families. The participants included sixty three parents of children with intellectual disability from UAE. Majority of parents were mothers, and were below forty years of age. In this study the researcher sought to expand the understanding of families of children with a disability in UAE by making use of a wider range of relevant variables. It examined the nature of the relationship between selected i.e. child and parent characteristics, family adaptation, ways of coping and parenting satisfaction. They completed three scales related to parent stress, ways of coping and parent satisfaction. The result showed that there was significant relationship between emotion focused coping and family adaptation. Also problem focused coping and parenting satisfaction. There was no significant relationship between other predictor and outcome measures. Majority of the families in the study reported that they had other children, while the remaining had only one that too with intellectual disability. Most of the children with intellectual disability were boys and were between six and ten years of age. Apart from this in another study that Khamis (2007) has been carried out with UAE families of children with intellectual disability, investigated child and parent characteristics and family environment in relation to parental stress and psychological distress though it did not explore family adaptation and satisfaction or parents’ coping strategies.
Bouke et al. (2009) in a research article on “Impact of caring for a school-aged child with a disability: Understanding mothers’ perspective” They explored various dimensions that challenge the mother’s performance in her role as a caregiver. A sample of eight participants was selected using a combination of intensity and maximum variation sampling. This sample consisted of Victorian mothers of school-aged children with a disability who were willing to share their stories. Semi structured interviews consisting of broad open-ended questions were conducted. All participants acknowledged that mothering a child with disability included emotional aspect with daily stressors and challenges to mental health. They even identified the time of their child’s birth or diagnosis as a very difficult time for them. Other issues that were even more challenging were related to the responsibilities that the mothers accepted related to their child’s needs and behaviors. Mothers’ days and homes were highly structured because of the child’s need for proper routine, therapy interventions and medical assistance. Families who had other children, apart from child with disability also expressed anxiety and guilt regarding coping mechanism. Only few mothers had extended family support and rest managed alone. Financial problem and issues regarding access of services, their adequacy, availability, the cohesion of services and their role as an advocate and coordinator were some challenged dimensions discussed by mothers. Most services were described as difficult to access and retain. They even highlighted lack of availability, consistency and funding for needed services and supplies. They themselves had to spend a lot of time and emotional resources planning, locating and retaining services for their child. Social stigma and social reactions also came up as major issues. It also indicated that care giving required the highest level of organization, endurance and overall cognitive ability.

K .Davis &S. Payne Gavidia. (2009) conducted a study on “The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities.” They took the sample from several early childhood intervention programs from metropolitan city Melbourne, (Australia). The aim of the study was to investigate the relationship between parental perceptions and experiences with family centered professional care giving and family quality of life. The sample consisted of sixty four families of children aged between three and five years with a developmental delay or disability. Most of the respondents were biological mothers and ranged in age from twenty five to sixty five years. Families had between one and four children living at home, including their child with a
developmental disability. The families of sixty four children with a disability or developmental delay were taken and questionnaire was completed. Parents reported speech or language impairment, global developmental delay, physical disability, down syndrome, dandy walker syndrome and dravet syndrome. Parents completed twenty five item of family quality of life scale and yielded five dimensions including family interaction, parenting, emotional well being, physical well being and disability related support. Other scales such as measure of processes of care, child behavioral problems or hassles were required to rate their perceived satisfaction with support from family members outside their immediate family were also completed. Findings showed evidence of the importance of a family focused approach to intervention. It also acknowledged and provided support tailored to the unique needs of each individual family. Studies suggested that families that are physically and psychologically healthy are able to facilitate and promote child’s well being and growth in a better way. This in turn led to the belief that early childhood intervention programs can indirectly influence children by focusing on other aspects of the family system and enhance families’ quality of life. Results showed that parental perceptions and experiences with service providers were relatively positive. Support from friends were rated higher than extended family members. A significant positive correlation between parental perceptions and experiences with family centered support and satisfaction with family quality of life was found. Parents who were living with a partner reported greater satisfaction along with professional support. The results also provided evidence that suggested that parental perceptions and experiences with family centered professional support are associated with families quality of life. In fact, professional support was found to be one of the strongest predictors of family quality of life. This result of the study highlighted the significance of delivering services to families of children with disabilities in a supportive and respectful way so that parents feel that they are being given equal treatment. Certain characteristics of child were related to family’s quality of life. Child behavioral problems being a significant predictor of family outcomes and revealed that such behaviors were exerting its greatest influence on emotional well being. Family income was found to be a significant correlate of family quality of life, parents with higher incomes reported greater satisfaction with their quality of life. Since higher income families have more resources thus can manage and cope with various issues that arise during their child’s
disability. The study proved that support that is tailored to the unique needs of each individual family as given by, is significant.

Heykyung . Oh & Lee Eun-Kyoun Othelia g. (2009) conducted a study on Caregiver burden and social support among mothers raising children with developmental disabilities in South Korea. The respondents in this study showed a high level of overall burden, specifically in financial area. Greater burden on care giving burden for the mothers was related to increased disability-related costs and some factors related to mothers younger age and high level of educational and lower social support. The study put forth that since disabilities brought with it extra financial burden which proved to be powerful forecaster of increased caregiver burden. Lastly it was also reported that social support can reduce this burden.

Jegatheesan et al. (2010) took a comprehensive view on “From symptom recognition to services: How south Asian Muslim immigrant families navigate autism” examined the experiences of three south Asian Muslim immigrant families who had a young child with autism and how they faced serious issues in their lives. Sample consisted of the three multilingual families from South Asia (Pakistan and Bangladesh), who practiced Islam and lived in a large mid western city in the United States. Parents of three families were in the age group between thirty and forty years and had lived legally in United States for approximately ten to fifteen years. Each family shared at least three languages (Hindi, Urdu and Arabic). Two families had numerous extended family members living in close proximity, and the third family was a single family unit with no relatives in the area. Each family had one son with autism who participated in the study. The audio recorded interviews were conducted at the families’ homes. Open ended questions led to conversations. The interview topics centered around four areas: diagnosis and parental reactions, parent perspectives regarding etiology and treatment, parents’ experiences with professionals and efforts to obtain suitable services. The results showed that parents found the process of obtaining diagnosis quite stressful and parents preferred to go to professionals who were of same cultural and linguistic background to discuss further. The common responses in the three families, when they were told about their child’s disability were shock, disbelief, perplexity and anxiety. Parents also reported that doctors never explained related issues in a simple and understandable language. They used medical terms which added an extra pressure on the parents’ minds. They also did not view their extended families as a resource for coping with the diagnosis, as
some relatives interpreted the child’s condition using superstitions or beliefs which blamed the mother as cause of present condition of their child. Parents also reported that they were advised by the doctors to attend support groups however they were not comfortable with support groups because they felt lost and knew no one. They did not appear to be comfortable with the idea of speaking about their concerns publically. Although parents were very active in the education of their children within their home, they were not able to advocate for their children or for services in the community. Lack of knowledge about services contributed to a lack of collaboration between family and providers around services. Parents also reported that professionals failed to understand their family based practices and as a result families discontinued some services.

Cohen (2010) wrote a paper on “Impact of a handicapped child on the family.” The objective of the paper was to identify awareness of the effect a handicapped child may have on the family. In this paper particular disability was taken into account because disability brings parental reactions in certain stages. Every parent anticipates great excitement and expectations with the birth of their child. The excitement may become mute with the birth of child with a disability of any type. The family into which this child born, is bound to change in many ways. Birth and upbringing of a child with a disability in a family is itself a stressful experience. General reactions of the parents towards disability include shock, depression, guilt, anger, sadness and anxiety. At times parents search for specific causes of their child's disability. Some parents may find a genetic basis as the cause and receive counseling regarding future children. These parents tend to consult professionals, try new diets, drugs and therapies. Over the period of time as they meet other parents they learn to accept their child’s disability and develop tolerance, appreciation for their child’s uniqueness and possess pride in his assets. Through these group experiences parents learn how others have coped, worked to find solutions to common problems and this can greatly reduce the guilt and stress. Some of the parent organizations have become active lobbyist on behalf of their children, secured legislation to provide educational, recreational and vocational services.

Gallagher et al. (2010) in their study on “Perceived needs of grandmothers of children with disabilities.” investigated the perceptions of twenty grandmother caregivers related to their concerns and requirements in caring for their grandchildren with disabilities between the age of three to twelve years with disabilities. The
grandmother caregivers ranged in age from thirty years to over sixty one years. Seventy five of whom were African American and twenty five percent were Caucasian. Some of them had autistic grandchildren. A number of children came to live with their grandparent as a result of family disruption, death of a parent, neglect, parents’ inability to meet the child’s needs due to their own physical or cognitive impairments. Surveys were completed via telephone. The questions were related to the need for grandchild, resources needed to understand those needs and concerns regarding grandchild with special needs. Results showed that grandmothers raising grandchildren with disabilities did have unique needs, including informational needs, respite needs and strategies for dealing with issues such as behaviors and language difficulties that may be related to the disability. They also shared that once they were given specific information they would be able to meet the needs of their grandchildren with disabilities in a better way. Apart from this, on the positive side, several grandmothers mentioned that they were happy to raise the grandchild and hoped the decision was correct. In a similar kind of study Minkler et al. (1997) demonstrated that grandparent caregivers have close to twice the rates of depression as other grandparents of children with disability.

Dillenburger et al. (2010) in their findings on “Living with children diagnosed with Autistic spectrum disorder: Parental and professional views.” assessed the experiences and needs of families who have a child with autism. Sample consisted of ninety five parents who had a child with autism. The mean age was forty years. The family autism needs questionnaire was specifically designed for this study to investigate the needs of families with children diagnosed with autism. Data was analyzed using statistical package from social sciences .Results showed that the majority of the parents felt that deficits in their child’s social and communication skills, lack of self-help skills and lack of getting proper sleep caused most difficulties. Most parents and professionals agreed that having a child with autism spectrum restricted the family’s ability to plan and pursue recreational and leisure interests, social and community interests and go on holidays or family excursions. Majority of the parents had been in employment in the past. However, some of the parents stated that their commitment to their child affected their availability for full time employment. Siblings were thought to experience feelings of being neglected, treated unfairly and isolated from their friends. Parents and professionals also agreed that there were times when families require general support such as family or respite
services and these services were not adequately available. They experienced significant distress while seeking funds to support their children’s treatment and education. Parents also found that disability allowance, mobility allowance or other allowances were very less. Some of the parents considered the impact of having a child diagnosed with autism more as a challenge than a restriction. Majority of the professionals had noted that parents faced considerable stress or difficulties when trying to access home, residential or respite support. Most parents and professionals agreed that increased support, information and training should be made available to parents of children diagnosed with autism. They were worried about present unmet needs and planning for the future. They also argued that educational and social service supports are not competent and they were forced to depend on support from within family or from friends.

Stevens (2010) in his paper “Disability, care giving and interpellation: Migrant and non-migrant families of children with disabilities in urban Australia” examined the experiences of parents of students at a special developmental school, comparing parents who were born in Australia and those who were born overseas. All Australian and New Zealand citizens and permanent residents are eligible for the universal health care system, medicare. Medicare covers medical fees as determined by the government with any gap to be paid for by the individual or a private insurance plan. Children who are diagnosed by a medical professional as having a disability are registered with the national social security organization, centerlink. Parents are categorized at this time ‘carers’ to receive the ‘Carer Allowance, a fortnightly payment that helps with the extra cost of raising a child with a disability. In the area of education Australian parents do not make decisions about their child’s education alone, rather a variety of specialists are involved. Early intervention is offered to pre-school children who are referred to doctors or other specialists by local maternal nurses. Even entry to special schools is possible at any age if the child has any kind of disability. In this study respondents were divided between migrant and non-migrants. They were asked questions about their family arrangement and their migrant history about the variety of migrant visas they have come on. Parents were asked to describe the challenges they had experienced, and the successes they achieved through open ended questions. Of all respondents who had families in Melbourne, only sixty six percent said that they relied on their family for help when they are sick. Success was felt across both group in areas of getting therapeutic and recreational services for the
child, and milestones in area such as personal hygiene and communication. Both
groups of carers were found to be worried about the future and their greatest worry
was, who would look after their child after their death. Despite difficulties, migrant
parents were just as happy, felt connected and used government services as Australian
born parents did.

Levy et al. (2010) in their article “Adjustment characteristics of healthy
siblings of children with autism”. compared parents’ self reports with self reports
from twenty seven children who have siblings with autism and twenty seven children
with no disabled sibling. Parents were asked to report on the child behavior checklist
and complete a Weinberger Adjustment Inventory in order to assess their own account
of their social and emotional adjustment. All parents of children with autism in the
southern region of Israel were asked to participate if the child attended a special
education setting for children with emotional disabilities from preschool to high
school and the child lived at home and did not have another sibling with a
developmental disability. The sample included twenty seven healthy siblings of
children with autism, between the ages of six and twenty one and fifteen were female.
Researchers visited the families’ homes. Results showed that parents who have to care
for a child with autism may not have time to arrange extra curricular activities for
their healthy children. It is likely that much of their attention is concentrated on taking
care of the disabled child and they may not find time to locate, enroll and drive their
healthy children to after-school activities. Another possibility is that the family’s
financial resources are directed to aid the disabled child. This would make it difficult
to pay for extracurricular classes and activities for the healthy children in the family.
Self reports suggest that for siblings same attributes maybe a source of distress.
Findings suggest that counselors and parents may assist siblings to lessen possible
emotional distress by lowering expectation of assistance and by facilitating their
participation.

Miller et al. (2011) in a study on “Impact of disabilities on families:
Grandparents’ perspective.” explored grandparents’ experiences of caring of a child
with disability, the impact on their family relationships and quality of life. In this
study semi structured interviews were conducted with twenty two grandparents of
children with disability. Four key themes were characterized such as grandparents’
views about their function in the family, holding own emotions, self sacrifice,
maintaining family interaction and quality of life for family in the future. In the study
it was found that grandparents were central to family functioning and quality of life, but this involvement came with a significant cost to their personal well being. Implications for policy, practice and research were discussed, particularly fear of grandparents’ was that their family could not cope without their support.

Trute et al. (2011) in their research on “Mother positivity and family adjustment in household with children with a serious disability.” explored maternal positivity as an emotional coping resource related to family adjustment in these families. Sample included all families of children less than eighteen years of age with first entry to disability services in previous three to twelve months. Majority of the participants were mothers. Other participants were fathers, grandparents, step or adoptive parents, aunts/uncles and foster parents/guardians. Interviews were taken on the telephones. Respondents were screened for eligibility and considered if they were a caregiver over the age of eighteen, who were able to complete a telephone interview. Telephone interviews were conducted once (time one) and again one year later(time two)The conclusion suggested that older mothers, with higher positivity at time one, showed higher levels of family adjustment in the longer term. On average family adjustments scores were within the normal range of adjustment at both times i.e one and two. Mothers’ age emerged as an important variable. Their age at time one showed a weak relationship to family adjustment. At time two, this predictor variable was a significant joint predictor of family adjustment. That is, older mothers with higher positivity scores were found to live in households with higher levels of family adjustment after one year. Results also supported mothers’ positivity as a psychological coping resource, which is related to enhanced family adjustment in situations of childhood disability.

Krenawi et al. (2011) in a study on “The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence” took random sample of three hundred Bedouin-Arab parents with one or more intellectually disabled children. Apart from that random sample of hundred parents whose children were not intellectually disabled also took part in the study. Data were collected about socio demographic variables. Questionnaire consisted of sixty items on seven dimensions of family functioning. A total of four hundred families participated in the research. The results showed that families with an intellectually disabled child have more awkward family functioning, less marital pleasure, more caregiver trouble and a lower sense of consistency than families without intellectually
disabled children. Infact, married couples reported high family functioning and the implications of marital discord for families with intellectually disabled children. In Bedouin-Arab culture the presence of an intellectually disabled child could be highly stigmatized especially for mothers.

Nankervis et al. (2011) in her article on “Why do families relinquish care?” investigated the factors that lead to relinquishment into out-of-home respite care aims to investigate the factors that lead to families relinquishing care, the factors that could put a stop to relinquishment and the outcomes for families/carers after relinquishment occurs. For this thirty two clients records (of individuals for whom families have relinquished their care in a defined twelve month period) were reviewed. Staff members involved with these families were also interviewed to provide more information. Relinquishment refers to families giving up the caring role of their family member with a disability. This generally led to the family member with a disability being located in an out of home respite facility until permanent accommodation can be arranged for that person. In this study seventeen staff members were interviewed in order to confirm the correctness of the information contained in the case file. The mean age of the sample was twenty years with the boys being younger when compared to the girls. The majority of the clients came from a two-parent family. According to the files the majority of the individuals were classified as having severe or profound disabilities. The majority of the cases reviewed involved individuals who were showing signs of challenging behaviors. Results showed that the cause for relinquishment was the need for continuous attention, when behaviors got worse as the individual grew older, and carer incapability to control behaviors as the individual became physically bigger and stronger and tremendous risk of injury to the carer or other sibling. Partial communication was another characteristic that appeared to be linked to relinquishing care. The emotional condition of the primary carer was an added cause for relinquishing a child with intellectual disability. The mothers of the family members with high support needs also reported to feelings of segregation and getting no support from within their families. The nature of the relationship between the parents in some instances was the main contributor to relinquishment. In some cases relinquishment was possibly linked with parental anticipation that their family member with a disability had the same right as their siblings to change into out of home permanent accommodation living when they reached adulthood. The interviews
with staff recognized the need for strategies and interventions which included teaching parent strategies while the individual is young in order to avoid the development of demanding behavior, arranging marriage relationship counseling before the relationship is an emergency and handling for carer depression. It was also found that some families, carers experienced positive outcomes after relinquishment. However feelings of blame and bereavement were found in some.

Rozanna Liley (2012) in her research work “It is an absolute nightmare: Maternal experience of enrolling children diagnosed with autism in primary school in Sydney, Australia”, examined the problems and experiences of the mothers who wanted to enroll their children with autism in a primary school. This study was carried out in Sydney, one of the major cities in Australia. Sample consisted of twenty two mother of children who were diagnosed with autism and who were about to commence their first year of school education. The ages of children were between four and six having diagnosis of autism, asperger and pervasive developmental disorder. Out of twenty two children nine children had further diagnosis of intellectual disability. The interviews were taken place at participants’ homes and mothers were asked to tell their practical experiences and steps they went through of their child’s school placement. Each interview was recorded. Results showed that parents reported that when their children were diagnosed with autism or intellectual disability they were intimidated to enroll their child in a Catholic school but they had a view that school chosen would not be able to offer required support. One mother during an interview reported that she was told that school can’t fulfill child’s special needs. Another mother was told by school principal that her child would bring scores down in the school. Overall the study gave an upsetting picture of prevalence of stigma of disability in the schools at primary level.

Muhammad Waqar Azhem et al. (2012) in a study “Anxiety and depression among parents of children with intellectual disability in Pakistan”. noted that parents who have a child with disability often face high level of depression especially in Pakistan where disability is still considered as stigma. Intellectual disability is very common in Pakistan. In this study sample consisted of 198 parents out of that 99 were fathers and 99 were mothers. The mean age of mothers were 37 years and fathers was 42 years. Children who had mild, moderate, severe and profound intellectual disability were taken up for this study. They even had a associated disability including cerebral palsy, mental health problems. Most of the parents had
feeling of embarrassment, shame and were disappointed that their child. It was found in study that parents had high level of stress and mental health problems due to social isolation and dissatisfaction. Most of them were dissatisfied that their child will not reach the career standards. Likewise in other countries like India, China and Pakistan also mothers are the primary caregivers of their children and had more stress as compared to fathers. They felt constrained in pursuing their social and leisure activities. It was also found that father had less anxiety and depression as compared to mothers and where child had associated disability added extra burden on the families.

Koa Whittingham et al. (2013) in a study “Sorrow, coping and resiliency: Parents of children with cerebral palsy share their experience”. highlighted the grieving, coping and resiliency experiences of parents of children with cerebral palsy. In this study 94 parents taken part and were asked to complete the Adapted Burke Questionnaire on chronic sorrow. It has been found that most of the parents reported grief, feeling of discrimination as well as feeling of guilt, dissatisfaction and exhaustion. Parents were worried about their children socializing with others especially when they enter high schools. Parents reported that they lost friendships after their child got a diagnosis of cerebral palsy even parents had a hard time when their child got diagnosis. Parents reported that they got devastated when their child failed to reach an expected developmental milestone. On the other hand it was interesting to know that many parents emphasized the importance of staying positive and believed that rather looking at negative aspect of their child’s disability they should find the coping strategies to cope with the situation such as seeking support from friends, family members or getting professional assistance such as respite support. Parents’ also found helpful to share their experiences with other parents who were in the same situation and had a child with disability. It has been found in many studies that having a child with intellectual disability in the family affects relationship between partners.

D. Norlin and M. Broberg (2013) in a study “Parents of children with and without intellectual disability: Couple relationship and individual well-being”. found that couples who raise a child with disability do have an impact on their marital relationship. In this study, data was collected through questionnaire from two set of groups. One group consisted of 104 parents out of that 58 were mothers and 46 were fathers who had child with intellectual disability and other group was control group where the couple didn’t have a child with disability. Many studies have found that
raising a child with intellectual disability had a tremendous affect on parents relationship and situation got worse when child with a disability displayed behaviors of concerns as well. It leads to stressful relationship and greater marital dissatisfaction. There were 178 mothers and 141 fathers in the control group. In both the groups different results were found. In this study it was interesting to know that marital quality didn’t differ in between groups but co–parenting system was a different. Only mother who had a child with intellectual disability reported lower wellbeing as compared to control group. On the contrary fathers had higher well being than mothers across groups and the reason could be that in most of the families it was the mother who was the primary carer. This study also emphasized that couple who have child with disability should receive the attention /care of professionals who should make appropriate intervention or put them in a right direction.

Faye Lin et al (2013) in their research “Caring for a child with severe intellectual disability in China: The example of Rett Syndrome”. explored the daily experiences of mothers and one grandmother caring for a child with Rett Syndrome via telephone interviews. Rett Syndrome is a neurodevelopment disorder characterized by normal early growth and development followed by slowing of development, loss of purposeful use of hands, typical hand movements, slowed brain and problem with walking and intellectual disability. Rett Syndrome is mostly found in girls than boys. In China, like in India people who have child with disability believes that disability is a punishment given by God for bad actions from a past life and persons with a disability are considered as a disgrace in the society. In this study parents whose child suffers with Rett Syndrome were interviewed with interview schedule via telephone. The questions consisted of functional ability of child, their social and educational experiences and worries about child’s future. Sample consisted of 14 mothers and one grandmother caring for a child with Rett Syndrome. Results indicated that Chinese parents reported that it took so long for them to get/find their child’s diagnosis which they found was annoying. They also felt that there were not enough rehabilitation services and no trained health care professionals who could tell them or explain them about their child’s diagnosis and appropriate intervention. Parents whose child was taking anti epileptic medication were worried about possible effects of its long term use on their children. In addition to that it was difficult for parents to buy a size suitable wheelchair for children who had a physical disability along with Rett Syndrome. This study further showed that cultural thinking and
restricted opportunities to interact with people with disability were probably to play a role in existing stigma not just in China but possibly other developing countries as well as such in India. In this study parents found that support groups proved to be vital source of information of parents about the management of a disorder.

S. A. Samadi and R. Mcconkey (2014) in their research “The impact of Iranian mothers and fathers who have children with autism spectrum disorder”. studied the impact on parents having a child with autism and how stress affects their emotional wellbeing. In this study thirty eight mothers and forty five fathers volunteered to participate. Most of them were married except five respondents who were single mothers. All participants had muslim background and more than half of them were educated at a university level. There were three scales applied included General Health questionnaire (Goldberg and Williams 1991), The Short form of parenting Stress Index and Family Functioning. Interview schedule was prepared which consisted of consisted of objective type questions and some open ended questions related to parents’ experiences and their problems having a child with disability in the family. Results indicated that Iranian mothers reported that parenting a child with autism placed a enormous stress on them which consequently leads to poor health. More stress was found among mothers than fathers. Parents who had university education reported good health because those parents were competent enough to access information about autism through internet and reading books. In addition, it was found that parents who lived with extended families were having lower stress as compared to single parenting. Furthermore higher amount of stress found among parents whose child displayed behaviours of concerns.

Conclusion

The comprehensive review of the above studies shows whether in any country the parents of children are bound to face stress and problems. Even though they may be financially stable, the burden of bringing up the child with intellectual disability is bound to show its impact. Though the governmental and non governmental agencies are working towards the welfare of intellectually disabled children and their families but still are unable to cater to the needs of their large population in developing countries .Where intellectually disabled in developed countries are concerned the issues of concern may be different such as long waiting time but the issues persist.