CHAPTER II

REVIEW OF LITERATURE

Disability-concept and classification:

The term disability is used to refer to functional limitation of an individual's ability to carry out the normal activities of daily living caused by either a permanent physical or mental impairment or a chronic clinical condition such as epilepsy, bronchitis, or schizophrenia (Reynolds, 1987).

The terms disorder, disability, impairment and handicap are sometimes used interchangeably, but actually have different meanings (Williams, 1987). Disorder is the broadest of the four terms. It is a disturbance of normal academic, psychological, or social functioning. Disability in WHO's(1980) classification system denotes the consequences of impairment in terms of functional performance and activity by the individual and the term disability refers to excesses or deficiencies of customarily expected activity, performance and behavior. The term impairment is usually reserved for any injury, damage, or

defect which prevents normal physical or mental functioning. All these terms refer to problems within the individual and fourth, handicap is an environmentally or socially imposed related limitation. Children with physical, sensory, psychological or learning problems are handicapped in a classroom environment that does not accommodate their learning needs (Brolin, 1982).

Another important term used in the context of disabled children is 'exceptional' or 'exceptional children'. It is an inclusive word that refers to children with physical disabilities, children with learning and behavior problems as well as children who are intellectually gifted (Heward & Orlansky, 1988).

Disabilities range from mild to severe and have a number of categories. The major disabling conditions include mental retardation, physical and health impairment, learning disability, behaviour disorder, hearing impairment, visual handicap and communication disorder (Miller & Schloss, 1982). Since the present study is concerned only with mentally retarded children and their families, the concept of mental retardation will be discussed in detail.

Mental retardation refers to a developmental delay

associated with intellectual and adaptive functioning that is substantially deviant from the general population (Brolin, 1982). Because of the varying degrees by which functioning can be impaired across academic, social, personal and career-vocational skills, mental retardation designates a highly heterogeneous group of individuals (Nizam, 1988).

Mental retardation has been defined from a psychological and educational frame of reference by the American Association on Mental Deficiency (AAMD) in the sixth revision of their Manual on Terminology and Classification in Mental Retardation (Grossman, 1973). It states, "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, and manifested during the developmental period". "Significantly subaverage" refers to performance on psychological test of intelligence of more than two standard deviations below the mean. "Deficits in adaptive behaviour" results when the individual is unable to meet the standards of personal independence and social responsibility expected of his or her age and cultural group. Developmental period is up to age 18 years (Ysseldyke, 1981).

Four levels of mental retardation are delineated under

the AAMD definition, mild, moderate, severe, and profound. In the AAMD classification system, the concept of mentally retarded includes, 'mild' (I.Q. 50-55 to approx. 70)", "moderate" (I.Q. 35-40 to 50-55), "severe" (I.Q. 20-25 to 35-40) and "profound (IQ blew 20 or 25 unspecified)" (Drew, 1984). These words minimize negative sterectyping. Some educators also use the classification "educable mentally retarded, trainable mentally retarded and manageable mentally retarded". (Smith, 1994).

From a purely statistical - theoretical view point, 2.27 percent of the population should score low enough on an IQ test (below about 70) to be classified as retarded. A number of writers indicate however, that only 1.68 percent of the school-age population is identified as retarded (MacMillan, 1982 and Neis Worth & Smith, 1978).

Causes of mental retardation include biomedical as well as cultural factors. Biomedical causes account for about 20-25% of mental retardation (AAMD, 1973). Example of some of the 200 biomedical causes are: prenatal infection of rubella; mechanical injury at birth; postnatal injury; various metabolic, nutritional, endocrine, or growth dysfunctions; prematurity; encephalitis; drugs; anoxia; and sensory

deprivation.(Grow 1981). Most retardation(75%)particularly mild type, is considered to be cultural-familial (Khan & Mirza, 1989).

The mental retardation is attributed to genetic and environmental limitations rather than biological or organic factors (Miles, 1988). In the case of persons identified as moderately to severely retarded, causes are more easily determined. These causes, are due to genetic factors or brain injury : Down Syndrome, phenylketonuria (PKU), and Tay-Sachs disease (Milunsky, 1983; Khan & Mirza 1989). Down Syndrome is due to chromosomal abnormalities and is linked to the age of the mother and possibly other factors, such as the age of father (Mirza 1989).Brain damage can be the result of infectious disease-for example, meningitis, encephalitis, and rubella - or environmental hazards and accidents.

Disability in Pakistan:

When the state of Pakistan established, the field of special education was in the hands of voluntary organizations. A few schools were run at Lahore, Bahawalpur, and Karachi by voluntary organizations, but there was no policy support to special education on Government level.

In 1958, Mohtarma Fatima Jinnah made a start by encouraging the establishment of the first teachers training college 'Gung Mahal' at Lahore, providing training to the teachers of deaf children (NISE, Bulletin, 1988).

The significance of educating disabled children was first identified by the Federal Ministry of Education in 1959 (AFMR, 1991). It appointed a commission known as 'The Sharif's Commission' to analyse the existing provisions of special education in the country. The report of the commission was considered carefully by the Government. It recommended that educational program of the handicapped children should include provisions of general education, vocational education and medical services.

At that time there were not a single school for mentally retarded children in the country. In 1960, the first day care centre for mentally retarded children, namely 'SCINOSA' was established in Karachi by a voluntary association (Report, Bureau of Curriculum and Extension, Sindh, 1982). This encouraged other voluntary agencies to come forward and work for the welfare of disabled children. Many other centres for children with hearing, visual and mental retardation were established during this period at Lahore, Rawalpindi and Peshawar (Report, DGSE, 1983).

Research work on disabilities was until an area which was not attended by any agency either at government or non government level. In 1969 the first research project on the incidence of mental retardation was undertaken at Karachi, with the collaboration of UNICEF and Jinnah Post Graduate Medical Centre. The study reported that 3% of the population appeared to have mental retardation of which 0.4% were severely retarded (Hasan, 1971).

Later, in 1972, the Federal Ministry of Education, framed the new education policy, with the objective of equalising the access education by extending the services for people with disabilities in cities as well as the under privileged groups in rural areas. The establishment of Voluntary organizations serving the disabled persons was encouraged and handsome grants were provided (DGSE, 1986).

An era of new awakening started from 1977, when President Muhammad Zia-ul-Haq, the Chief Martial Law Administrator started taking an interest in the field of special education. Placing education and special education among highest matters of priority, he directed the Ministry of Education to review the state of education in the country and develop new plans and projects, specially for the disabled

children (NISE, Bulletin, 1988). The special education department was transferred to the social welfare wing of Ministry of Health (Special Education and Social Welfare Division, 1989). Four model special education centres for hearing, visual, mental and physical handicapped children were formed by the government at Islamabad.

In February 1985, the Directorate General of Special Education was setup as a technical part of the special education and social welfare division under the Ministry of Health, Special Education and Social Welfare (DGSE, 1986). In the light of the national policy on special education the DGSE initiated a number of projects such as the establishment of the National Institute of Handicapped (NIH), National Training Centre of Disabled (NTCD), Special Education Sequence at the universities etc. A scheme was evolved by the Directorate General of Special Education to establish a network of 40 selected sites for special education centres, at provincial and divisional levels in all the four provinces of the country (Hunzai, 1991; DGSE, 1986). Directorate General of Special Education (DGSE), utilizing all its resources very successfully managed to pass through the process of forming these centres.

The Government promoted various schemes for comprehensive rehabilitation of disabled persons e.g. 'Employment and Rehabilitation Ordinance 1981'. The most significant feature of the ordinance is fixing a 1% quota of jobs for disabled persons in all agencies. All establishment were required to pay Rs.2000/- in lieu of each of the unfilled post to the National Council for Rehabilitation for every month. The ordinance also allocated 1% funding for the disabled for admission in educational or professional institutions with financial allocations recognizing their special needs (Social Welfare Report, 1989).

To fulfill the training needs of the teachers working at special education centres, the National Institute of Special Education (NISE) was established in 1986 (AFMR, 1991). The organization of introductory and orientation courses in special education was undertaken by N.I.S.E, Islamabad, utilizing local experts (NISE Bulletin, 1989).

In 1986, a national plan of census of disabled persons was designed by DGSE. The pilot study was carried out on the population of two cities, Islamabad and Rawalpindi by way of door to door survey (UNICEF, 1991). The survey of two million families gave a prevalence rate of 2.6%, more or less equal

among the rural and urban groups. Children 0-4 years constituted 12% of those disabled; 5-9 were 15.7% and 10-14 were 15% of the total, with children above the age 14 constituting 43% of the total disabled population. Of these, 33% were classified as physically handicapped, 21% intellectually impaired, 15% visually impaired, 8.7% hearing impaired and 19% multiple handicapped (Rawalpindi, Islamabad Survey, 1986).

A similar research project namely 'Rapid Epidemiological Assessment of Childhood Disability' started at Jinnah Post Graduate Medical Centre, Karachi, in 1986 with the collaboration of Colombia University (Mehar, 1991). The study included medical and psychological assessment of the surveyed group of 2-9 years old children. The study added the prevalence of any impairment at 574/1000, all disabilities 209/1000, for moderate disability 46/1000, and 17/1000 for severe disabilities. The rural rates were generally double to those of the urban sample and for severe disabilities. Besides, the rate of disability was higher for boys than girls (UNICEF, 1991).

A collaborative link with the international agencies like, Overseas Development Administration (ODA), World Health

Organization (WHO), United Nations International Children Educational Fund (UNICEF), UNESCO, UNDP, and ILO was developed which brought forward many fruitful schemes for the disabled population. In late 80's and with the beginning of 1990, a number of international agency funded projects was initiated in the country. The nature of coordination included availability of equipments, advisory services, translation and adaptation work, preparation and distribution of reading materials etc., (Social Welfare Report, 1989).

In the recent years, various community based rehabilitation projects as well as out reach programmes started in various cities of Pakistan i.e, - Karachi, Charsadda, Sargodah and Dera Ismail Khan (CHD, 1993). The objectives were to provide facilities of education and training to the maximum number of disabled children. The year 1993, termed as the SAARC Year of disabled (South Asian Association of Regional Cooperation), brought many valuable provisions for the disabled persons. A number of workshops, recreational programmes and other related activities took place during the year enlightening significant aspects related to the teaching and rehabilitation of disabled children (SAARC, 1993).

Disability and the family:

"The family is a unit of people who live together and share life's basic day-to-day function".

[Dodson & Kurpius (1977)]

A family is a social group characterized by common residence, economic cooperation and reproduction (Chaudhry & Khan, 1988). It includes adults of both sexes, at least two of whom maintain a socially approved sexual relationship and one or more children, own or adopted (Murdock, 1975). The family functions as a system of interaction, and the way it conducts personal relationships has a very powerful effect on the psychosocial development of children (Muhammad, 1992). Infants born into a family soon learn that they are separate individuals: that their existence is distinct from their mother's, their father's, and that of other members of the family. Even an infant learns that these members of the family have desires and interests to which they must at times adapt.

A traditional nuclear family consists of four sub-systems (Turnbull, Summers, & Brotherson, 1984): Marital subsystem - husband and wife interactions,

Parental subsystem - parent and child interactions. Sibling subsystem - child and child interactions, and Extrafamilial subsystem - whole family or individual member interactions with extended family.

The marital subsystem consists of interaction between husbands and wives. The presence of a child with an exceptionality, however, can have an impact on their relationship and interactions (Rabia, 1991). Many studies have indicated that having a child with a disability can have a *negative impact* on the parents marriage. Featherstone (1980) noted: A child's handicap attacks the fabric of a marriage in four ways. It excites powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family. It creates fertile ground for conflicts. Divorce, marital disharmony, and husbands' desertion have been reported to be disproportionally high in marriages where there is child with an exceptionality (Gath 1977, Murphy, 1982, Reed & Reed, 1982).

The parental subsystem is composed of interactions between parents and their children. Parents can be affected in their interactions with their child depending on whether

their child is a son or a daughter. Some fathers, regardless of social class, have shown a greater initial impact if their child is boy, and mothers a greater impact if their child is a girl (Farber, Jenne, & Toigo, 1960; Miles, 1981). Tallman (1965) found fathers to be more adversely affected presence of a disabled son than a daughter, and cope less skillfully than mothers in raising either a son or a daughter.

The sibling subsystem is composed of sibling interactions. Grossman (1972) conducted one of the most well-known sibling studies and found that approximately 45% of the siblings reported that they had benefited from having a sibling with an exceptionality. The benefits included more tolerance and compassion, greater understanding of other people, increased awareness of prejudice and its consequences, and greater appreciation of their own health and intelligence. In a study on siblings of disabled children, in Pakistan, it was found that they experience both negative & positive feelings while interacting with the disabled child (Amin, 1991). Siblings do take the responsibility of care-taking of the disabled child. Siblings in a two-child family, however, experience special pressure regarding education and care of the disabled child, particularly when the sibling is a son (Grossman, 1972; Amin, 1991).

The extrafamilial subsystem is composed of family or individual interactions with extended family members, friends, neighbours, and professionals. Extrafamilial interactions can make a major contribution to the progress of the child with an exceptionality, as well as provide parents with a network of support (Farida, 1988; Muhammad, 1992). In Pakistani families, it is observed that the responsibility of care for the child is equally shared by other family members (Nasir, 1990). These persons are the source of various kinds of support in many families (Miles, 1988).

Disability and family characteristics:

By family characteristics is meant family characteristics as a whole: its size and form, cultural background, socioeconomic status, and geographic location. Each shapes the family's responses to an exceptionality, and each serves as a potential resource to help the family cope with the child's disability.

Much of the research on families with members with exceptionalities suggests that larger families tend to be less distressed by the presence of a child with an exceptionality (Trevino, 1979; Sajida, 1989, Humaira, 1989).

A large number of siblings may be able to absorb parents expectations for achievement that, in two-child families, often seem to fall on the shoulders of the only child without an exceptionality (Powell & Ogal, 1985; Amin, 1991). In addition to the number of children, the number of parents in the household may cause a difference in a family's reaction to the exceptionality (Farida, 1988). In Pakistan, the family size of an exceptional child is not vary different from that of normal children (Sajida, 1989). Parents do not prevent child birth even if they have a disabled child (Miles, 1983).

Family values and life styles in some cultural groups serve as source of strength in coping with an exceptionality. For example, in Pakistan, families provide support to each member and thus encourage parents to work for the disabled child (Tareen, 1989). Not only the parents display educational involvement but other family members (e.g., an aunt or grandmother) also take interest in the educational decision-making of the child (Muhammad, 1992). Families in Pakistan tend to have strong kin networks into which a child or adult with an exceptionality can be enfolded to provide support for such needs as financial management, child care,

and emotional support (Farida, 1988). Families with these resources may not have such great need for formal community services (Miles, 1983).

The social status implies that a higher socioeconomic status family might have more resources available to cope with a disability. But, the equation is not that simple, higher socioeconomic status does not automatically guarantee better coping. Lower socioeconomic status families may also have resources (Khan, 1980). Because higher socioeconomic status families are often more achievement-oriented, they may consider an exceptionality involving a mental or physical disability as a severe disappointment of their aspirations for their child's future. Lower socioeconomic status families on the other hand tend to value achievement less than other values such as family solidarity or happiness (Lee, 1982, Rubin, 1976; Miles, 1991; Munavver, 1993).

The values of rural and urban families may differ. Although families themselves may be more similar in value and form, there are some very different problems associated with providing special education services in rural areas (Mehar, 1991). Most of these problems have their roots in scarce services and the distances between families who have children

with exceptionalities. While isolation may be problem for many families. a rural family may experience even greater isolation if there are no other families in their immediate community whose children have similar situations(Miles, 1983; Cole, Smith and Ranken, 1981). In the context of Pakistan, it is strongly recommended that special education services may be extended to rural areas (Miles, 1981; Mehar, 1991; Munavver, 1993).

Disability and family function:

Families exist to meet the individual and collective needs of their members (Baqai, 1985), e.g., economic, domestic, health and care, recreation, socialization, self-definition, affection, and education/vocation (Turnbull, Summers, & Brotherson,1984). In each of these areas the responsibibility [illegible] of [illegible] the [illegible] family members [illegible] is [illegible] transfered from the older to the younger generation (Brotherson, Backus, Summers, & Turnbull, 1984).

The presence of a member with disability can create special economic needs by increasing the family's consumptive demands and decreasing its productive capacity

(Arshad, 1983; Turnbull et al., 1984). In one study, 29% of the families reported that their child's physical disability had created a financial hardship (McAndrew, 1976). Other studies found out that for some families, the child's special needs can include costly medical bills, expensive equipment, or excessive expenses on schooling and transportations (Rizvi, 1972). Most Pakistani families with a disabled child face these problems (Munavver 1989; Nusrat, 1989; Sajida, 1989; Mumaira, 1989; Muslim, 1992; Alia, 1993).

Not all children or youth necessarily cost a family more or affect its ability to generate income. In fact, in some situations the child may even cost the family less care because the child may not be requesting such expensive items as new video recorder, personal computer, or car (Khan, 1974; Miles, 1981).

Families meet the physical and health needs of their members (Arshad, 1983). For some parents, the child's domestic and health care needs create stress, which often increases over the life cycle as the child's needs increase (Qadir, 1992). Families domestic and health care needs vary depending on the type, degree, and severity of exceptionality (Humaira, 1989). For example, a child or

youth with a sensory loss probably will not create the same extent of domestic and health care demands as one with severe mental retardation (Husain, 1973).

The family serves an important function as an outlet where members can relax and be themselves (Arshad,1983). Sometimes this function is curtailed with the presence of a family member with an exceptionality. Some families have reported that they had difficulty enjoying family outings such as trips to the beach, picnics, or trips to cinema (Dunlap & Hollingsworth, 1977; Lonsdale, 1978; Rabia, 1990). Program objectives for leisure and recreation activities often have been accorded low priority in the educational process (Khan, 1974).

Another important aspect, socialization is vital in determining the overall quality of life (Muhammad, 1974). For most individuals, families are the bases from which individuals learn to interact with others. It functions as keys in the achievement of socialization for all members (Arshad, 1983). Many families experience stress in attempting to meet socialization needs (Rabia, 1991). A review of the literature on social development of children having exceptionalities in Pakistan concluded that

"almost all exceptional children, regardless of their disability, have significant social handicaps" (Miles, 1983).

Family provides important opportunities for meeting the needs of physical intimacy as well as feeling of unconditional love and esteem by others (Arshad, 1983). A child with an exceptionality can have both a positive and negative impact on a family's ability to be affectionate (Turnbull, Summers, and Brotherson, 1984). For example, a family can be drawn together and experience a close sense of bonding as a result of the exceptionality. A negative impact can also occur in families with members who are exceptional. Some families may fail to establish affectional bonds with the child who is disabled either because of the fear that the child will die or leave the family, or because the child is physically deformed (Featherstone, 1980; Lowe, 1985; Miles, 1991).

Family memberships play an important role to help individuals establish who they are and their worth as people. Exceptionality can have an impact on the self-identity of all family members (Samina, 1991). Parents of children with disability often experience loss of their own

self-esteem (Qadir, 1992). Parents inability to accept a disability may also greatly affect the ability of the child with an exceptionality to develop a healthy self-identity (Miles, 1988; Durdana, 1989; Samina 1991).

Educational/Vocational needs is the area that professionals often emphasize more than families (Humaira, 1989; Sajida, 1989; Rabia.1991). This is appropriate if the emphasis is consistent with the family's value and cultural priorities. If not, the difference between the focus of school, other services agencies, and home can cause strain or possible conflict in the home and school relationship. As in Pakistani culture, more emphasis is placed on educational achievements of the child than vocational training, the educational situation becomes conflicting. (Shabbir 1989). Parents or the child can respond negatively to a perceived over-emphasis on educational/ vocational needs (Husain, 1978).

Family perceptions of disability:

Perception of disability by the family provides variations of ideas (Miles, 1991). Family members mostly relate the child's disability to physical weakness, health impairment, attention problem and poor comprehension (Dawood,

1992). Some of the parents are not aware of the fact that the child is actually having a problem and go for medical services to find a quick solution of the problem (Sajida, 1989; Rabia, 1991).

Parents as well as siblings of mentally retarded children do not appear to be fully aware of the child's capabilities (Miles, 1983; Nasir 1989). They want the child to develop and study like other non disabled children (Dawood, 1992). At times, they expect too much from the child. The educational plan parents have for the child is not only unrealistic but clearly reveals their inability to perceive the child along with his disability (Qadir, 1991).

In a study on family perception of children in NWFP, Pakistan, it was found that learning is perceived either as book learning i.e., memorization or as obedience to master, teacher or parents (Miles, 1991). Skills such as walking, talking and communicating are believed to be acquired automatically as the child grows. Parents are unaware of the range of normal behavior as well as the limitations of a disabled child (Dawood, 1992; Munnavver 1993).

Children with learning problems are perceived as

'stubborn'. The common comments by parents are, 'he won't obey, he is stubborn, he won't read or write, he won't talk properly, he won't listen, etc.,' (Miles, 1991). Parents want their child to learn and reach a high level of education, e.g pass matriculation examination, do graduation etc. Other skills are expected to be a product of the aging process and not learning (Rabia, 1991: Munnavver 1993).

Parents of young retarded children regard walking and talking as important, but are less concerned about self feeding, toilet training and dressing (Miles, 1983). They may regard preliminary skills as irrelevant, unless a careful explanation is given of the purpose of preliminary skills in constructing more complex skills (Humaira, 1989).

Parents do have a view of child development but without the sequence of learned skills. They do not understand that due to the child's disability, he has certain special needs and may need individual attention to learn such, they do not feel the significance of child centred approach or developmental method of education (Munavvar, 1989; Azra, 1989; Humaira, 1989; Miles, 1991).

Parental unawareness of the range of normal

developmental abilities, together with not appreciating the value of the experiences of childhood, results in mentally retarded people being regarded as separate, different groups, rather than as people who happened to be at the lower end of the spectrum of learning ability (Miles, 1991). A different view of learning may cause parents difficulty in understanding that children can be taught the skills they have not acquired automatically (Humaira, 1989; Rabia, 1991).

Misconception and poor parental perception about mental retardation is related to a number of variables. The major responsibilities lies on poor educational facilities, poor medical guidance, poor communication through media, lack of community based education, non availability of literature on the topic in the local languages and other similar factors (Sajida, 1989; Rabia, 1991; Dawood, 1992; Bashir, 1992; Qadir, 1992; Abbasi, 1993).

Family attitude towards disability:

Attitudes and reactions to the handicapped are wide ranging and complex (Siller, 1976). They are based on variables related to and important to attitudinal formation (e.g., family background, culture, and personality). Age, sex, and other demographic variables

appear to be significant determinants in the manner in which attitudes towards the disabled are expressed rather than in their formation (Muslim, 1992).

The effect of the birth of a retarded child on his parents reaction is of overwhelming shock or pain, followed by a sense of guilt, and shame (Lowe, 1985; Nasir, 1989). It is a stigma on the otherwise well placed family to have a defective child (Miles, 1983). All these facts lead to the development of parental attitudes toward disability.

Studies in Pakistan indicate that the most common parental attitudes toward the disabled child is rejection (Muslim, 1992). Parents appear to be eager to get rid of the child one way or the other or put him in an institution and forget the problems caused by him (Qadir, 1992). The child is considered as insufficient and unpresentable before others (Rabia, 1991; Alia, 1992).

The expense incurred to provide training to the child is perceived as waste of money and effort (Alia, 1992). It is felt that nothing can improve the child's condition, or if any progress is achieved it would be limited. The child can

not become doctor, engineer, clerk or school teacher, (Miles, 1983; Muslim, 1992). Thus it is no use spending money on him even though thousands of rupees may be spend upon the education of the other siblings in the family (Humaira, 1989; Alia, 1992).

The attitudes of parents of disabled children are influenced by the attitude of societal members (Miles, 1983). Although there is some evidence that low socio-economic status parents may be more rejecting (Holt, 1958, Khan & Chaudry 1980), most researchers have concluded that high socio-economic status parents evidence greater difficulty in accepting their disabled child (Downey, 1963; Meadow and Meadow, 1971; Muslim, 1992).

The attitudes of high socioeconomic parents are the result of the higher achievement expectations these parents have for their children; when the child is disabled, the parents experience greater disappointment because their child cannot "measure up" (Tareen, 1989). On the other hand lower socioeconomic status families may suffer more adverse effects because they do not have the financial resources to gain assistance in caring for the child (Gallagher, Beckman, & Cross, 1983; Nasir, 1989, 1990).

The sex of the disabled child may also affect parental attitudes (Miles, 1983; Muslim, 1992). It has been observed that in lower socio economic families, having a mentally retarded boy had a more acute effect on marriages than did having a retarded girl; but the sex of the child was not related to marital integration in middle class families (Sajida, 1989). In some families having a handicapped first-born son was more distressing to parents than having a first-born handicapped daughter, or later - born disabled son (Meadow & Meadow, 1971; Alia, 1992; Munavver, 1993).

In an extensive study of the family adjustment, it has been found that disabled children do have an effect on the siblings (Amin, 1991). The effects of exceptional children on siblings is related to the age of the siblings and the socio-economic condition of the family (Farber, 1959, 1972; Grossman, 1972). Research seems to indicate that children are likely to reflect the attitudes of their parents towards handicapped children in the family (Grossman, 1972; Klein 1972; Miles, 1991). If the parents perceive the child as a shame or burden, other children in the family will react in the same way. If the parents accept the child as a full member of the family, the siblings will do likewise (Amin, 1991; Miles, 1991).

Families interviewed in a study in Pakistan reported that siblings of retarded children resented the attention given to the disabled child: they were also ashamed and embarrassed (Amin, 1991). Frequent fighting, bossing, jealousy and embarrassment on the part of the non disabled siblings was observed. Siblings are more likely to evidence feelings of anger and resentment toward a disabled sibling than they have toward a non-disabled brother or sister (Seligman, 1983; Miles, 1991).

Siblings of disabled children are usually effected psychologically by a family member's disability, either directly or indirectly by the disability, and by the degree of parental deprivation, anxiety, and successful coping (Davis, 1975; Bashir, 1992). Studies on siblings of disabled children indicate the presence of feeling of indifference about their sibling. More probing indicated the presence of guilt they felt over their indifference and hostility during childhood and adolescence (Amin 1991, Samuels & Chase, 1979)

Family expectations and aspirations for the a disabled child:

The family of the disabled child attaches both realistic and

unrealistic expectations with the child (Muslim, 1992; Mehar, 1992; Qadir, 1992, Alia, 1992). The disabled child is expected to perform like normal siblings and achieve all that parents desire or plan for them (Miles, 1991). In a study at Jinnah Post Graduate Medical Centre, Karachi it was found that mothers and fathers over estimate their retarded children's potentials: those most over-rated are the younger and more severely retarded children (Farzana, Zahida, Yasmin, 1989). However, regardless of the degree of handicap or age of the child, mothers of retarded children over estimated their potentials for future achievement (Nasir, 1989; Asmna, 1991; Rabia, 1991).

It seems that regardless of type and degree of disability, parents may hold to unrealistic expectations and aspirations for a disabled child (Sajida, 1989; Nasir, 1989; Miles, 1991). In a study, mothers of deaf children have been shown to be unrealistic about child's education, selection of occupation and ability to adjust in future employment and life settlement (Fireman, Makim and Hastings, 1975).

Studies have documented that parents of handicapped children may display unrealistic expectations about a child's

future, but they are not unrealistic in their appraisal of current functioning (Miles, 1991). In another study mothers of mentally retarded children reported high estimations about the child's future but were quite realistic about the child's present level of functioning (Munavver, 1989).

Several studies have focused on parental expectations for their child's school achievement (Chapman & Boerema, 1979). Findings indicate that mothers of disabled students demonstrate more negative reactions to their children's school achievement behavior, more negative interaction for the child's ability to interact with other and lower expectations for future school performance (Hiebert, Wong and Hunter, 1982).

In an investigation, when ratings of mothers of non disabled students were compared to mothers of the disabled students, the later more often expected that their children would perform poorly in school and assigned them significantly lower rankings in their ability to express themselves, pay attention, follow directions and get along with other children (Bryan, Zimmerman and Mathews, 1982).

Siblings appear to be more realistic in developing expectations and aspiration for the disabled child. In a study at the Karachi University, it was found that though the siblings have high aspirations for the disabled child but their expectations regarding his achievements in future is quite realistic (Amin, 1991).

Problems of families with a disabled child:

Families of disabled children face numerous problems in their day to day life (Sajida, 1989; Humaira, 1989; Rabia, 1991; Bashir, 1992; Qadir, 1992). The major once listed are marital problems, decision about additional child, practical problems of relationship with the family members, socialization, health, expenses and stigmatization.

Having a disabled child may adversely affect the marital relationships. Studies have found that tension and stress result from parents arguing and worrying about their mentally retarded child (Farber, 1959, Schonnell and Watts, 1956; Miles, 1983; Rabia, 1991; Bashir; 1992). Similarly, parents of a psychotic child have been reported to argue about how to handle the child and to blame each other for the situation. These behaviours lead to marital discord

(Marcus, 1977; Farooq, 1989). There is evidence of high rates of divorce in families with a mentally retarded child (Price - Bonham and Addison, 1978; Rabia, 1991).

The experience of having a disabled child may result in parents deciding not to have any more children. It has been seen that parents of retarded children do not want to have any more children and that their decision seem to be a direct result of having a disabled child (Holt, 1958; Rabia, 1991). Parents of deaf children also try to limit further issue. (Freeman, Malkin and Hastings, 1975). In Pakistani families, however, parents do not appear to take the issue so seriously (Miles, 1983; Rabia, 1991).

Parenting a handicapped child presents many practical problems (Nizami, 1988; Abbasi, 1988; Sajida, 1989; Ahmed, 1989; Rabia, 1991; Qadir, 1992; Miles, 1982, 1991). Studies have shown that the birth of a disabled child in a family results in increasing parental responsibilities, changes in family life, change in roles of family members, increased emotional pressures on the family members, and increased need of help from professionals (Bagai, 1988; Akram, 1990; Rabia, 1991, Qadir, 1992).

Relationship with extended family members may also be disturbed due to the presence of a disabled child. Main problems include experiencing feelings of guilt and shame for having a disabled child by the parents and siblings (Lowe, 1985). Parents find difficulty in going to social gatherings and feel ashamed when some of the relative ask about the child's disability (Rabia, 1991; Qadir, 1992).

Studies in Pakistan exploring the role of extended family members in the life of disabled children have provided differing results. Some findings are in favour of the extended family members and suggest that their presence help to reduce the parent's pressures created due to the child's disability (Bashir, 1982). While others found out that the presence of extended family members might create conflicting situation. The responsibility of parents is shifted and as such the child is faced with a situation which may create ambiguity for him (Rabia, 1991).

Numerous studies have documented the restrictions having a disabled child places on the social life of parents (Rizvi, 1972; Arshad, 1985; Muhammad, 1992). They engage in far fewer leisure time activities together and interact socially less with friends (De Myer, 1979; Londsdak, 1978;

Lei, 1973 McAndrew, 1976: Rabia, 1991: Qadir, 1992). In a study, parents of mentally retarded children reported that they avoid going to public places, social gathering and recreational places because of the child (Akram, 1991).

Studies of families in Pakistan indicated that having a disabled child affected the emotional health of parents (Munavver, 1989). Parents of disabled children display physical and emotional exhaustion (Qadir, 1992, Miles 1991). The physical energy used in the day to day care of the child often led to serious mood variations in parents. Along with the physical strain, parents also reported the presence of emotional pressures like depression, worry, guilt, and shame (Munavver, 1989).

Families have often reported the additional expenses associated with having a disabled child e.g., modifying the home structure to accommodate the child, repairing damages done by the child, and so forth. (Gumz and Gubrium 1972, Lloyd-Bostock, 1976,:McAndrew 1976). Pakistan is a poor country with limited resources. Majority of the families have limited income and a number of heads of expenditure to be met (Baqai, 1988). In such a situation, the extra expenditure on the disabled child creates great problems for the parents (Arshad, 1983).

Parents have reported feelings of being isolated and stigmatized by their neighbours (Freeman et al., 1975. Holt, 1958 Miles 1983). In Pakistan, community member reactions towards disability is pity, staring and pointing which make parents feel like out casts. (McAndrew 1976; Stone, 1948; Nasir, 1990; Nusrat, 1990; Alia, 1992). They are conscious of themselves and feel stigmatized for having a disabled child in the family (Nasir, 1990).