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**2014 PARENTS' PERCEPTION ON SPECIAL
CHILDREN'S EDUCATIONAL NEEDS
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By

Naveeda Saddiqu

Department of Sociology

Quaid-i-Azam University Islamabad

2014

Quaid-i-Azam University, Islamabad
(Department of Sociology)

FINAL APPROVAL OF THESIS

This is to certify that we have read the thesis submitted by Ms. Naveeda Siddique, it is our judgment that this thesis is of sufficient standard to warrant its acceptance by the Quaid-i-Azam University, Islamabad for the award of the Degree of "M.Sc in Sociology".

Committee

1. Dr.Muhammad Zaman
Supervisor



2. Prof.Dr. Anwar Alam
External Examiner



3. Dr.Muhammad Zaman
In-charge Dept. of Sociology



This is certifying that the thesis submitted by Naveedasaddiqu is of sufficient standard to warrant its acceptance for award of degree of Master of Science in sociology.

Supervisor approvalsignature _____

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ABSTRACT

Disable children are facing problems in the Pakistani society. Major problems are due to the behavior of family and community. Parenting a special child is a great challenge in general but especially in Pakistan. It requires mental and physical strength. Qualitative research method was used for study. The research was done in NIRM Islamabad. 10 cases were taken to study through case study method. The study found out that stigmatization was most important problem for the disable children's parents. The researcher found that along with other factors family has strong impact on development and grooming of special child. Conservative thinking that parents' sin brought the disability of the child was found in the research.

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Chapter No. 1

INTRODUCTION

Disability may be defined as “disturbances in the functioning of social functions. Which are ordinarily be expected of a person in the habitual milieu, arising in connection with a diagnosable mental disorder”. The term disability, impairment and handicap are often used in a confusing and interchangeable fashion.

Disability refers to certain restrictions which capacitate a person from doing. It with draw him or her from power of acting. The term is perceived differently in Pakistani society. Some people believe that it is a curse from God and atonements is sought by sacrifices, charity or going to the holy places. Some relate it to their own deficiencies. They produce a feeling of guilt. It results in isolation of disabled child by hiding him from others. Some have no idea about what is wrong with children. A few perceive it as a sort of mental illness. When parents discover that their child has a disability or a chronic illness, they begin a journey that takes them into a life. It is often packed with strong emotion and relations with many different professionals and specialists, and continuing need for data and services. Initially, parents may feel cut off and unaccompanied. They do not know where to begin their search for information, aid, understanding, and support.

Special children need special types of care and training. Children with special needs will do some things in a different manner from other children. What works fine with other children may not always work fine for them. From the

day of birth, they are treated differently. They require special care and attention. Parents of children with disabilities have many reactions to their children's special need. These reactions may be positive or negative. Some parents experience sorrow, unhappiness and embarrassment because of the pain which their children have to experience. It also causes anxiety for parents themselves. The most stressful situation occurs when parents came to know that their child's disability is not fixable. They try to determine that what the best educational options are for their child. They wonder that how their child will survive as adults. These decisions are difficult and it continues throughout childhood and adolescence and sometimes into adulthood. Reaction of parents also depends on severity of disability. Moreover, culture is another important factor. In some cultures, disability is a sacred incidence that may reveal a loss of the soul in an earlier lifetime. In other families, a child with a disability is considered as a sign on the entire family. In some families, a disability is recognized as just part of who the child is.

Mothers who give birth to handicapped child experience mental upset followed by a diversity of neurotic symptoms. There is also parental feeling of denial. Stigmatization by family environment also has an adverse effect.

Costs of disability are paid by not only the affected individual, but also family of that individual. They have to face economic and physical hardships. Social isolation is also suffering. The effects are commutative and may make an

already difficult situation unbearable for families with a disabled child. Like other children a disabled child is also born into a family and remains a lifelong member of that family. Among all social institutions school, community, peers and family, family are most important. Family exerts the most the most significant influence on a child's development as it provides love, concern, sustenance, protection, guidance and direction to child. Every family being different from other provides a wide variety of living experiences for children. The life of a disabled child is interwoven with that of family. The way parents and siblings treat a special child is a reflection of attitude they have for disability. These attitudes are a product of child's age, sex, severity of disability. In the process of attitude formation, parents reach to the state of passive acceptance actively. They involve themselves in education and care of child. While parents who do not resolve the emotional reactions tend to express negative attitudes towards children.

The treatment of children by different family members may also be a different. Positive attitude leads to the healthy development of children. Negative attitude might develop unease in childhood and affect his emotional and social development. In Pakistan, in a joint family most likely having grandparents, uncles and aunts in a house. The messages to children are most likely to be conflicting in nature. In small nuclear family there is likely to be greater compatibility. A child with disabilities may find a passive and rich

atmosphere. Some families also have a negative and restricted atmosphere depending on the circumstances present in the family at any particular time.

Parents are not alone to bring up a child. Many preexisting factors share their attitudes towards child and the job of rearing. The attitude of other children, their parents, and the extended family member's act are significant determinant of their behavior. Moreover, background factors existing even earlier in the organization of the family, such as social class attachment, religious affiliation and social status may also mold the way in which they deal with the task of rearing the child.

Disabilities range from mild to severe and have a number of categories. The major disabling circumstances include mental retardation, physical and health impairment, learning disability, behavior disorder, hearing impairment, visual handicap and communication disorder. Mental retardation refers to a developmental delay associated with intellectual and adaptive functioning that is significantly deviating from the general population. A cause of mental retardation includes biomedical as well as cultural factors. Biomedical factors consist of mechanical injury at birth, nutritional deficiencies, drugs, anorexia and sensory deprivation. There are also certain levels of retardation.

The majority of parents wish to have their child learned in a normal school. This may be for the reason that there is still a stigma attached to 'special' schools. Many children with statements flourish in the ordinary classroom as

long as the support they need is provided effectively. The disabled child is posing a great problem to the world. It was calculated that by the year 2000 there will be at least 600 million disabled people. The present conditions of 125 million children, who are disabled, belong to developing countries.

1.2 Who are special children?

Children with these problems are called special children and they have special educational and other needs.

1.1.1 ADD/ADHD

ADHD (Attention Deficit Hyperactivity Disorder) is a neurobiological disorder characterized by developmentally inappropriate impulsivity, attention, and in some cases, hyperactivity beginning in childhood, "typically" by the age of 7. Children with ADHD often have a 2-4 year developmental delay and frequently have other coexisting conditions.

1.1.2 Autism

Autism is a complex developmental disability that typically appears during the first three years of life. It is a brain disorder that affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. People with autism are not physically disabled and 'looking' just like anybody without the disability. Those with high-functioning autism may have speech and intelligence intact. Others may be mentally disabled, mute, or have serious language delays.

1.1.3 Blind

There are over 50 definitions of blindness worldwide. The World Health Organization definition of blindness is less than 3/60 in the better Seeing Eye.

1.1.4 Cerebral Palsy

"Cerebral" refers to the brain and "palsy" to a disorder of movement or posture. It is not progressive. Prenatal causes of cerebral palsy include illness during pregnancy, premature delivery, and lack of oxygen supply to the baby caused by premature separation of the placenta, an awkward birth position, labor that goes on too long or is too abrupt, and interference with the umbilical cord.

1.1.5 Developmental Disabilities/Mental Retardation

An individual is considered to have mental retardation based on the following three criteria:

- 1) Intellectual functioning level (IQ) is below 70-75
- 2) Significant limitations exist in two or more adaptive skill areas
- 3) The condition is present from childhood (defined as age 18 or less)

Others are;

1 Down syndrome

2. Sensory disorders

3. Speech disorders

4. Spinal Bifida

1.3 What are their Special Needs?

Special children need special types of care and teaching because they are different from normal children. Their behavior may seem new or these children grow in ways that are different from other children. They also need to learn in ways that are different from other children. What works well with other children may not always work well for them. They need a totally different environment to survive. Knowing more about the different kinds of special needs will help understand these children better.

1.4 Problems Faced by special children

There is sufficient indication that disabled children are less respected members of society as compared to normal children. Most children are of course social and very much conscious of separation. Disabled children rest out as strange, weird and abnormal, and may become targets for mockery and harassment. Sometimes special children live in a type of community where adults are not supportive, nor do they prepare the disabled child for repulsive encounters and unkindness from peers. They should learn that they do not deserve the unfair treatment they can reject it and should try to find the help of an adult when such situations present themselves. As these children are not

trained so they are very easy to access by people who can use them for their own benefit.

Children are remarkably flexible, but the psychological effects of physical and mental disability can be long-lasting. Beyond the noticeable effects of social instability, mental disability can lead to repeated uncertainty, disturbance, nervousness and annoyance. Disabled children internalize negative attitudes of peers and think they are less important and respected than others.

In families which are financially stable, children may be protected from the direct economic effects of a physical or psychological condition. Financial problems can have direct effects on the child, such as inadequate food, non-availability of necessary medications and uncertain access to medical care due to transportation hurdles. Parents of children with disabilities face great depression, fear, worry and more from loved ones and even family members, concerning their little angels with eyes of ill feeling, concern and even distrust they are really disabled at the time. Families can find themselves lonely from their support circles (family and friends) when dealing with a child that has special needs or disabilities. Extraordinary demands of their special child make them isolated from society.

According to the Vera Institute of Justice, disabled children are three times more likely to be sexually abused than their non-disabled peers. Among children with intellectual and mental health disabilities, the risk is 4.6 times

greater. Abusers search for children who can be easily manipulated and have the imperfect physical ability to oppose. Most abusers are not strangers, but someone the victim knows. Unfortunately, disabled children are hardly ever given the same opportunities as others, especially in developing countries. According to UNICEF, they are at a greater risk of poverty, and are less likely to attend school or receive medical care than poor children without disabilities. These children are often unseen from view. Additionally, children with disabilities are four times more likely to be mistreated, ignored and physically abused than other children; they are also more likely to be emotionally abused, both by their peers and adults.

1.5 Comparison of Provincial Disability Rates and Numbers

The analysis at national level shows that the highest rate of disability 3.05% in Sindh and the lowest 1.0% in Islamabad. Rural areas contribute 65.7% in the total PWDs population compared to 34.3% in urban areas at national level. Segregating data by gender, it is interesting to note that male population of PWDs 58.4% which is significantly higher than the female population of 41.6%. At national level 55.9% of PWDs live in Punjab and 28.4% in Sindh respectively. These two provinces bear the major share of total population of PWDs.

If we compare data at national level by type of disability, the crippled and Blind constitute 19.2% and 8.2 % of total population of PWDs respectively.

1.6 Statement of Problem

The study is aimed at studying perceptions of disability, expectations about disabled child and problems faced by parents of mentally retarded children. Perception of disability is identified by exploring parent's awareness of child's deficiencies, cause of disability, and presence of disability in other children. Identification of child special needs and need for special schooling for children.

Identification of parental attitude towards disability and its impact on child included parents idea that how people behave towards children ,child likes and dislikes, hope for positive changes, child's admission to special school, importance of school meetings, child's presence in social gathering as well as when friends and guests are around.

1.7 Objectives of the Research

1. To study disability.
2. To analyze the parental attitudes towards disabled children.
3. To identify nature of parental attitudes.
4. To investigate relationship between family attitude and development of child.
5. To find out reasons of disability.

1.8 Significance of the Research

As a sociologist it is a most important topic to conduct research upon it. The research on Disabled Children proved to be of very much significance, because this research remained successful in disclosing the various dimensions of special people in society. The number of researches has been conducted on this topic before; all those remained helpful in this regard. The study will be useful in many respects as parents are prime educators and first to attend to needs of special children. Besides siblings also play important role in life of a disable child. Study of perceptions of parents of disable children will clarify and identify relationship of family attitude with education of child. The research will be helpful in creating awareness among people regarding special children. Investigation of perception of disability will reveal how they see child disability, to what extent they are aware of cause, what do they feel about child special needs and possibility of arranging special education for child. Similarly exploration into nature of aspiration will identify the hope families attach for disable child in spite of deficiencies regarding education. Through this study people will know that like normal children education is also necessary for special children. In our society when parents come to know that their child is special they perceive that education is not necessary for them, but these children can also become productive members of society if attention is given to them by whole society especially parents.

This research will be helpful in disclosing true behavior of people toward disabled children in society. This research also reveals the mutual relationship of special people and society.

Problems identified by parents related to disabled child will assist people working in field of special education to design better strategies to be adopted while working with families of disable children. It will enlighten the area where most effort is required by service providers when involving parents in educating disabled child.

Since special education is relatively new field in Pakistan investigation will provide much needed information and helpful to encourage future research. Favorable parental attitude has brought to light by this investigation will encourage a new effective approach of parent involvement in the teaching of handicapped children.

Chapter No. 2

LITERATURE REVIEW

Process or state of being a parent is called as parenting. Morison defined parenting as the process of developing and utilizing the knowledge and skills. It involves appropriate planning for creating, giving birth to, rearing or providing care for offspring. The definitions of handicapping conditions are unclear. The diagnosis of condition may overlap with another condition or diagnosis may change time. Many special children remain undetected and often parents resist having their children identified as exceptional because of stigma attached to labeling. (Hallahan and Kaufman 1982).

Reactions towards special children depend on many factors. Attitudes vary among different families. Rearing of children and attitude towards them also depend on economic factor. In various socio-economic classes it is different. Middle class parents as a group exhibit anxiety symptoms over their child rearing procedures. On other hand the lower class less importance is given to discipline and its manifestations are less harsh (Horrock 1952).

Term disability is used to refer a certain limitations of an individual's ability. Carrying out normal activities of daily living becomes difficult. It can be caused by either a permanent physical or mental impairment or chronic clinical condition, such as epilepsy, bronchitis or schizophrenia.

Every 8th persons disabled either physically or mentally. During the civil war in Afghanistan 3.5 Lac men, women and children have become disabled. 4 million people were deprived of visual and hearing. According to world report

Australia comes at number 1, Finland is second and Hungary stands third for disabled people. Diseases, accidents and racial clashes are major cause of disability. During last decade 4-5 million children have become dependent on support to live a life. 8 % of population of Pakistan is physically or mentally disable, while 42million are deprived of visual and hearing. Now rehabilitation of special children is being celebrated (Goldenson 1978).

According to Physicians the delay in treatment causes complete disability in Pakistan. Insufficient diet in pregnant women, excessive use of drugs, infection during birth, and inevitable care during course of pregnancy is the reason of it. Except cousin marriages are also one of the reasons of it (Atif and Hassan 2001).

Another important term used in context of disable children is exceptional children. This refers to children with physical disabilities. Children with learning and behavior problems as well as who are intellectually gifted (Heward and Orlansky 1988)

Beside other problems, social handicap is also needed to be mentioned. It means the behavior of non disabled persons. They tend to avoid social interactions with disabled people. Peoples attitude towards disabled persons is always negative (Mentzaet et al.1997).

Resources required for raising a disabled child are three times more as compared to rising up a non-disabled child. Parents of special children

experience anxiety. Factors behind anxiety consist of the child's sleep and behavior problems, material resources, parents' employment situation, social support, and parents' coping strategies. Disabled children and their families often not have suitable local spare time facilities and reachable transport. They often face aggressive and unsympathetic attitudes from members of the public. These factors stop them from taking part in actions as an entire family (Barker 1948).

Children with behavior problems can many times be difficult to get a handle on. Child behavioral issues many times may be the result of learning disabilities (like dyslexia), may also have ADHD, be over tired, hungry, or any one of a number of other factors. If you as a parent react to children with behavior problems through anger, this could eventually turn into a discipline problem. Poor behavior may also be due to a lack of the parents' attention to the child. We all lead very busy lives these days, where two income families are the norm just to survive and get by. This lack of time and attention could in itself lead to the child not feeling wanted or loved. Therefore acting out to get your attention the only way the kid knows how Parents who make it a point to spend as much quality time with their kids as possible will many times avoid many child behavioral issues that occur.

The social status implies that a higher socio economic status family might have more resources available to deal with a disability. Although it does not

means that they are being brought up perfectly. Higher socioeconomic status families do not automatically guarantee better coping. Lower socioeconomic status families may also have resources. As higher socio economic 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 families on the other hand tend to value achievement less than other values such as family solidarity and happiness (Humaira 1989)).

Disability includes physical or cognitive deficiency. Disabled children face greater challenges but these challenges are more likely to occur in settings where resources are limited. Unavailability of resources is great challenge. Disable children are easier to access for abuse as compared to normal children. These children are discriminated and ignored. Protection of their basic rights can solve these problems. Only infrastructure need is not enough when these children are valued equally they can flourish and it is also supportive for family as well. Perceptions of disability by family provide variations of ideas (Mile1991).

Unawareness is also a problem. Some of 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 problems (Mayer 1992).

Pakistani government and people are working for the betterment of handicapped. The government would pay attention with commitment for the rehabilitation of disabled persons, especially to provide them health, education and employment facilities. On the international day of disabled persons president of that time Pervez Musharraf said

“I am pleased that international day of disabled persons is being observed on 3rd December, 2001 in Pakistan in accordance with UN Resolution 37752 of 3rd December 1982 on equalization of equalization for persons with disabilities. For the reason that they can make immense contribution to the social growth of the country if they are provided with enabling and supportive environment by the government and society in general” (The News, 3rd December 2001).

Emotional responses of parents are also important to discuss. There are three stages in this respect. First stage is of emotional disturbance, next stage is rejection due to guilt and shame and last stage is acceptance. Interviews showed both positive and negative responses of parents. Some parents argued that they have become more responsible, they have become more caring, but on the other hand some parents are not adjusted even after many years (Horrock 1951).

Public attitudes are often greatest obstacles for children with disabilities. Since publication of the reference bibliography "Attitudes towards handicapped children; past and present" the emphasis on disability has been shifting from focus on different-ness and limitation to a focus on abilities and potential .people with disabilities are participating more fully in the mainstream of society and are advocating for full acceptance. This approach led to the formation of U.S disabilities act (1990) which is found to be quite helpful in changing public attitudes (Karna 1999).

Stoneman and Crapps (1988) studied 104 women providing care for people with mental retardation in their homes. The three predictors of these women's perceived competence in the care giving role were the presence of a person with mental retardation in the caregiver's own family, positive attitudes of neighbors, and social support.

A number of researchers have either focused on parenting competence in families of children with disabilities as the primary dependent variable or have included measures of psychological distress alongside a measure of competence. Comparison designs have indicated that mothers of children with developmental delays report greater competence in parenting than do mothers of children with no delays, especially during the infant stage (Gowenet et al. and Haldy et al. 1990).

According to Biklen and Bodgan (1976) following are the common reactions towards the physically handicapped:

1. There is tendency to presume sadness on the person with disability, they are less likely expected to laugh or smile.
2. There is feeling to pity towards physically handicapped.
3. Disable people are not made to participate in normal activities. They are treated as children.
4. Feelings and emotions of disabled are ignored; they are not treated as human beings but like objects.

Parents have to face so many challenges regarding their special child which nobody can imagine. Special children are identified by disorders like autism, Asperser's, and bipolar disorder. There are so many websites and books and organizations but no one knows more than parents, usually all parents of special children have same problems faced.

One should not forget that every member of family has individual importance and every member of family might have his own problems. The personal problems, pressures upon family members of physically handicap children also affect the attitude adversely towards the special child and presence of family may add to these. For example father has stress of economic affairs. He worries about financial affairs, he is busy with job, and mothers also have

many problems to look after other than taking care of special child and needs of her other children. Special child is throughout the life is struggling to cope with his special problems and his brothers and sisters are picking up stress and tension around them. The important thing for each of them to recognize is that all families, whether or not they have special child, have to come to terms with similar feelings (Millards 1984).

The general attitude of public towards the special child is one of on difference or pity. Parents of a special child usually do not have a positive or encouraging attitude. It is mostly one of the shame and fear of social stigmatization, as well as an almost religious or superstitious view of handicapping as a manifestation of the will of God. In some instances it is viewed as of the wrath of God for their own prior sins. Such a situation requires a basic attitude change in the vast majority of people. Attitudes are not easily altered as physical states, so this will take long time indeed (Abdullah 1981).

There are also some religious or spiritual views about special children. Every child is a blessing from God and some parents after knowing that their child will be abnormal they choose abortion due to fear that there will be a burden on society, but this is wrong decision. As every child bears a message from God if only we open our hearts to it we can know this message.

Parenting a disabled child is really a great challenge and these parents need support but it is to highlight that that what outcomes parents require from that support, this research found eight findings. Personal identity is first aspect their personal relationships including interests and works played vital role in their sense of identity, second aspect of this research focused on physical and emotional well-being, caring a disabled child requires physical and mental strength, third aspect focused on skills decision making, communicating and supporting skills are required, these skills are needed because these children need extra ordinary care. Fifth aspect highlighted was that too much caring of special child causes lack of quality time spent with non-disabled child .maintenance of family life is sixth aspect extra care of disable children disturbs personal life of parents, sitting in family gathering becomes difficult especially for mothers relation with siblings is seventh aspect parents of special child need to have full support from siblings they need a positive whole family experience. Role of resources is eighth aspect parents need financial resources to cope up with child social needs; lack of resources is cause of stress for parents.

A movement of parents of mentally retarded children started in 1930 .It was extended in so in 1950 so in 1951 more people and groups can join on associate basis. Reasons behind this growth are to spread awareness that existing institutions are unfit and to spread sense of responsibility among people .These activities cover a wide range in favor of special children needs

regarding material and non-material needs. Funds raising started ,aid for education of mentally retarded children started .This all was nonprofit .a formal method was used including meetings ,parents came to know underlying problems, this was done by news bulletins and pamphlets (Manzoor 1984).).

Shortage of services also leads so many problems; one aspect is distances between families who have special children. For Rural areas isolation is greater problem, if there are no other families in their immediate community whose children have same situation (Miles et al. 1988).

Some parents reports difficulties in bonding process with children who are disable. There may be number of reasons behind this: the parents may be turned off, by the child's appearance, if the child is not responsive or attentive parents may give up trying to interact, if the child is at risk and is physically isolated from parents after birth, the opportunities of binds are diminished and parents may fear that child will die (Drotar et al. 975).

Chapter No. 3

THEORATICAL FRAMEWORK

3.1 Rational Choice Theory

Rational choice theory was proposed by Gary Becker in 1961. It proposes that Individual chooses action which is beneficial for him. Rational decision making entails choosing an action given one's preferences, the actions one could take, and expectations about the outcomes of those actions. All actions can be ranked in an order of preference. Rational choice theory is the view that people act as they do because they consider that performing their chosen actions has more profit than expenses. That is, people make rational choices based on their goals, and those choices rule their behavior. Some sociologists use rational choice theory to explain social change.

3.2 Application of the theory

This theory applies on topic in the sense that parents are less likely to educate their special children. They believe that special child cannot earn for them in future. They do not care for their educational activities because they are not able to give benefit to them in the future. Special child cannot be productive member of society, that is why parents do not find any benefit and do not let them study.

Chapter No. 4

RESEARCH METHODOLOGY

Research Methodology

Methodology in research is process, logics, systematic knowledge, key points and techniques for getting enough knowledge about research which a researcher wanted to conduct. Talking about parent's perception about Special children education and to know the level of awareness in them, researcher selected qualitative research method for study. Qualitative research method will provide in-depth information for researcher which fulfill primary and secondary key component for study. The in-depth interview schedule was compiled by researcher with the help of supervisor for conducting interviews in field work

4.1. Universe of study

For conducting research it was compulsory to select population for acquiring data. For understanding of systematic knowledge, collection of data and description the very first and most important step was to choose universe. The locale chosen for this research was Islamabad which is capital of Islamic republic of Pakistan. The research was conducted in Islamabad, National Institute of Rehabilitation and Medicine. According to requirement of the topic some houses of respondents were chosen. The hospital for conducting research was located in G-8-2 sector. Near "*Peshawar Morr*".

4.2 Unit of Analysis

To study the whole population was a tough, difficult and time consuming task for researcher. So in order to make it easy and possible, the researcher selected the sample size of 10 individual for conducting in-depth interviews.

4.3 Tools for Data Collection

Interview schedule was an important tool used to collect in-depth information from respondents. It was a detailed chart used for collection of in-depth information. The study conducted in-depth interviews in National Institute of Rehabilitation and Medicine to acquire the recommended information.

4.4. Technique for Data Collection

4.4.1 Case Study Method

Case study method was used during this research in order to get in-depth information about various events or incidents that might have taken place in the lives of disabled or special children being interviewed, showing the presence of any attitude of people toward them ,myths or superstitious. Role of parents, family members and siblings was also observed.

The criteria of collecting case studies was that there had to be a detailed narration of an event or incident by a disabled child, his/her parents or relatives that was related to peoples negative or positive attitude towards them, and which might have occurred in their lives at some point.

10 cases studies were taken during research. Among them there was number of cases including mentally retarded, polio cases, accidentally disabled, deaf and blind children.

4.4.2 Photography

Photographic technique was used during research to take photos of children whom parents the researcher interviewed. However, due to some moral issues I could not took photos of all my respondents.

4.4.3 Interview Guide

Interview guide was a list of points or topics, which the researcher covered during interview. Interview guide was administered to parents of special children.

The questions were such that knowledge of firstly parents themselves, family members and then common people about disabled children. They also probe into any existing myths that people believed in about the origin and causes of disabilities.

4.5 Opportunities and Limitation of Study

During research the researcher faced many problems; main problem was that some mothers did not want to give interview about their children. They took it very personal. It was difficult for the researcher to make them discuss problems of their children. The researcher also had to wait for them because

they came to hospital for their children sessions (physic sessions and speech sessions).So they did not gave much time for being interviewed.

According to requirement of topic the researcher also needed to visit houses of respondents. It was necessary to observe home environment which children were facing. Being a female researcher faced problems to stay in their house for long time.

4.6. Ethical Concerns

The researcher followed the moral tenets while conducting in-depth interviews. The researcher first politely took permission for interview from respondents. The researcher kept confidentiality of feedback of respondents. The researcher was successful in creating frankly relation with respondents.

Chapter No. 5

FINDINGS

I will start my findings with the empirical data. Shazia was a mother of 4 years old girl, Hafsa. She was suffering from Down's syndrome. She was living in the remote area near with sector E11 Islamabad. When the researcher went to meet her at home, she was busy in her daily household work. Her children were playing in front of the house. Shazia gave warm welcomed to the researcher in her house. After sometime, the researcher started the discussion with her about her family. She told that she has two children, one son and one daughter. Daughter (Dania) is elder than the son. Further she said that her daughter is abnormal.

When the researcher asked about the type of abnormality, she explained that when her daughter was born doctors said that she will not be able to carry her neck in future life, because there is a problem in her spinal cord. She carried her daughter in her lap and let the researcher see that her neck is very small and it is from birth. The little girl was good looking and beautiful. The researcher admired her. At the time of her birth when Shazia came to know that her daughter was abnormal she became depressed and upset. She said "Ahh Allah, why this happened to me, I did not commit any sin, but then she decided to live with "*sabr-o-shukar*' (patience).

She further said that her daughter gradually started recovering; when she was about 2 years old she started to carry her neck. After that she started walking at age of 2 and half years.

5.1.1 Superstitions

As Pakistani society is a male dominant society, desire of a son is observed in almost every family. Women are forced to produce son without realizing this fact that it's not in the hands of a woman to select the gender of child by her own wish. This research found that this type of stress can be transferred in expected baby. He/she can be affected by this stress negatively in the form of any type of abnormality. The research found this is one of the major reasons of abnormality in child.

“On asking about abnormality she told, that when she was pregnant she wished for a son and always prayed for a son and this thing affected negatively on her daughter. She became abnormal. There was no one having disability in her family before” (Shazia, mother of Dania)

At the time when she came to know that her daughter is abnormal, she was extremely disturbed. Her family members also put her under stress, but after 4 years their attitude has been changed. Her daughter was not able to understand what is right and what is wrong. She even did not know what to eat and what not to. Sometimes she also ate medicines. Respondent said she cannot look after her every time. She also has to look after her son.

5.1.2 Conservative Approach

The research found that people have conservative thinking. They preferred to go to “*Pirbaba*” for healing. *Pir baba* explained that this child is very near to God. This type of thinking was penetrated in the minds of people, especially women because women are more likely to believe in these types of things. There is possibility that child can be cured but conservative thinking of people does not allow them. They do not go for treatment to doctors. Their foremost preference is to consult a “*Pirbaba*”. It is popular in rural areas (urban as well but mostly in rural areas) that people go to different shrines for specific aims, to fulfill their desires. They do specific tasks there which are called “*mannat*” in local language. It is also found that when there is any difficulty afterwards they again prefer to go there. People are spiritually so much attached to these practices. Moreover, women are more prone to these practices as compared to men. It is also found in the research that even educated class society also has conservative approach. They think that their child’s disability is due to some sort of “*jadoo*” (magic). This type of approach is usually related with rural people but educated class is also indulged in these things.

The research found that superstitions were still prevailing in the minds of the people. People usually try to relate every disease with a superstition. With each action they believe that there will be consequences. It can affect their lives, and they have firm belief on it.

The respondent further told that she went to many “*Pir baba*” (spiritual scholar) and all said that your daughter is “*Allah lok*” (very near to Allah). They also advised her to never scold her daughter. He warned her that she will be in loss if she mistreated her child otherwise she will be given “*baddua*” (curse). The respondent had a strong belief that her prayers were always accepted whenever she was in some trouble and she asked her daughter to pray.

She was also blessed but sometimes her family members (in laws) used to treat her rudely. Family members say to her that she disturbs them, beat their children, and she creates mess in their rooms. The respondent explained very sad that she really felt depressed at times. Sometimes she lost temper and she became fed up then started abusing her daughter’.

5.1.3 Family mechanism and its relation with attitude

Family is universal and basic social institution, which is set of cultural traditions, beliefs and values. Within these the bearing of children, has been based .These traditions, beliefs and values are transmitted to the young individual to fulfill their potential of production, growth and development. Parents’ desire is to do their best for children by building strong families in community.

Families of the children with special needs require–different kind of social support in order to live equally like other families and to participate in society.

Many parents described that for many years they have taken two steps forward and one step back, they always think that what life could have been if the child have not been disabled. This means they spent their life in regret and desire of being normal life. Parents face many hurdles in their efforts to bring up their child who is quite demanding. Family support should be important for the adjustment throughout the life of special child. Family support is one of the protective factors. Social support from family relationships may provide a stress buffering effect, but there is less understanding of how relationships with parents may serve as protective factor.

Every child needs parents and families support and care to grow and develop. Among their basic needs like shelter, food and basic health care is the need for love and being valued and respected as individuals. It is to be expected that parents look for ways of curing the effects of any illness or impairment their child may have.

The present study aimed at studying the influence of parental attitude towards their disable children and also the perceptions of such children towards family support that how children perceived it. Some parents are able to understand the needs of special children and change their lifestyles accordingly. Those parents who are unable to face this situation feel frustrated, sadness and increasingly family stress.

Such kind of child from early childhood learns from his/her parent's siblings and from the people around him/her. Child perceives the attitudes of family either positive or negative. Parents are believed to exert their efforts and all energies to their special child and provide facilities in the life of special child. As the disability of child which is congenital, cannot be corrected but by the training, guidance and counseling the parents of disable children can enable the child live a fuller happier and satisfied life.

Parental feeling about the child's disability sets the friendly interaction with the disable children as the parents are basic and main source of learning and guidance for such child. On the basis of present study it was found that attitude of parents is an important factor in training, guiding and understanding the problems of such children, and also the most important influence on the development of the personality of disable children.

The present study aimed at exploring areas in which parents interact with their disable children and provide good direction and help to them. It was specifically conducted to measure the attitudes of parents as an effect of gender, age, education and socio economic status. Beside the perception of such children, perception on family support was also explored. It was observed that mothers have more positive attitude towards these children as compared to fathers.

Generally there is common social concept that mothers are more caring, loving and concerned about the child and with his/her problems. It seems that fathers are less concerned, less involved in child rearing activities. So, it was believed that others have more positive attitude towards their children. Special children need more care and attention as compared to normal children. Mothers seem to have sometimes sympathetic and sometimes empathetic attitude toward their children. But it does not mean that fathers do not have love for their disabled children, and this can be a misconception for the role of fathers in society.

Dania's Mother tried her best to take care of her needs. Although, sometimes it looked very difficult to manage and fulfill all her needs. It was difficult for her to take her along everywhere. It was more difficult to look after her outside the house. She was feared that somebody could take her as she couldn't understand anything. She wanted to educate her daughter and wanted to admit her in good school. When researcher acquired knowledge about her future plans about the child she said "I wanted her to become doctor of abnormal children but sadly she said "*jo Allah kimarzi*" (what we can do if Allah wants that).

Shaheen was a Mother of a 3 years old boy, called Hameed. Hameed was suffering from Cerebral palsy. He was living in a village near sector E11.

When the researcher went to Shaheen's house, she was busy having lunch with her children.

In rural areas mostly there are family patterns of solidarity. But still they are following the values of social solidarity at micro level or macro level. Rural people have their traditions and values. Solidarity is important factor observed in rural areas. The research found that a special child is even ignored in rural areas. There is a tradition in villages that whole family members sit together for having a meal but the special child is not adjusted in family environment. They face ignorance and discrimination.

The researcher observed that they all were sitting at a "*charpai*" (a bed to set). Three children were having lunch with their mother but fourth one was sitting on the floor in very dirty clothes. She stood up and welcomed researcher and offered her to have lunch. Researcher sat on a chair placed near and observed the environment. Any outsider can easily guess that this child is ignored once. After getting free from lunch, Shaheen came to researcher. The researcher started asking about her abnormal child. She spoke by looking hopelessly towards him and said he is abnormal.

5.2.1 Reasons behind retardation

There may be different reasons behind disability of a child. If delivery is done by mid wife there may be chances of complexities for mother as well as for child. One other reason found was cold. One of respondents told the

researcher that her baby was given bath immediately after birth and due to extreme cold it affected his brain and he became retarded.

5.2.2 Conservative methods vs. modern methods

The research found that modern methods of treatment are more useful. Doctors normally check the new born immediately after birth. This checkup is to confirm that child is healthy and fit. Latest technology has made it easy to diagnose any disease if occurring in new born. On the other hand midwives do not have these facilities. In fact they do not have the knowledge and awareness. So they cannot find out that newborn baby is not normal. It is found that doctors confirm the disability of child as midwives are untrained and unaware of so many facts.

When the reason of retardation was asked, she said that he born at home by the midwife and she was not properly trained. Also gave a bath to the baby immediately after birth, it was winter and that's why he got cold.

She further told that the main factor behind his retardation was "*daī*" (midwife). The respondent told that her son did not cry at the time of birth. She took him to doctor and doctor told her that her child is mentally retarded.

When she came to know about that she became very depressed. She said her husband was also tensed because when Hameed was born her husband was very happy. Allah blessed them with the son after 12 years, but his parents became hopeless that why this happened to them. Her husband and supported

her but inside he was also very upset, because the son was born after many “*mannat*.” (Praying in shrine for specific reason/aim). He was expecting good news but unfortunately he had to face this bitter reality. The researcher came to know from respondent that father of the child was more upset. Reason behind this was his second marriage. From first marriage he did not have any child.

About *shrine* and *Babacuring*, she told me that they went to shrine because she knew about a “*baba*” and his “*taweez*” (Charm) is very effective. Many people were cured by him but her mother in law did not allow her to go there, because she did not believe in these things.

When the researcher asked about care of child respondent said that her in laws (sisters of husband) look after him. One of the sisters is very kind and she takes care of him most of the time. She said she mostly remains busy with her other children, as her daughter goes to school. Her son is about 3 years and she also have to look after him.

She explained that her child is abnormal and his presence or absence is the same. It is extremely difficult to look after him, feed him, and clean him. His aunts look after him and take care of his needs. Her family behavior with him was satisfied. Mostly he played outside with street children. Sometimes he beats other children and her neighbors come over to complaint “but tell me

what I can do? My daughters go to school they do not have time to play with him, also he disturbs them a lot”

When being asked questions about education she said that there are special schools for these types of children. Due to lack of resource she did not send her abnormal child to school. She further said it is extremely difficult to send him to school and his future is not like other children.

Ayesha was physically handicapped girl, age 7 years with severe disability. She was two years old when she struck by heavy fever and as a result her legs damaged by polio attack. She could not walk without holding something. Her mother said that they also completed a course of polio vaccine at the time of polio attack.

5.3.1 Negligence at home

This also makes it clear that once parents send their disabled children in school they consider themselves free of all responsibility to help the child cope with his disability. This neglected attitude of parents make further problems because during training if child is made to walk it means he/she can be cured properly but parents do not have sense of responsibility that they also have to look after their child at home.

The researcher came to know that at NIRM Ayesha started walking without any support because the doctors gave her a lot of physiotherapy and training to walk. However in two months holidays her parents neglected her and did

not continue her exercise, so she lost her control on legs. Ayesha's parents belong to a poor family and have no enough sources for her treatment. She did not have wheelchair at home. Her house was near hospital. And her mother requested researcher to visit their house. She said that her daughter will be very happy if you come to our house. Ayesha was very loving she got attached with one nurse also which was her attendant.

5.3.2 Lack of resources

As a special child has special needs, along with extra time and care he needs certain extra equipment to cope with his disability but due to lack of resources it becomes difficult for him and his family to cope with this situation. Lack of wheel chairs and other aids at home slows the progress of child which he was making in hospital.

When the researcher visited to Ayesha's house first time she was alone in bedroom without light. She became very happy to see her. Ayesha could not speak as she spends most of the time with her grandmother who speaks Punjabi. She could not understand Urdu very well and the researcher could not speak Punjabi.

5.4 Case No. 4

Saeeda, was mother of Ayaan came to National Institute of Rehabilitation Medicine. Ayan was 4 years old suffering from speech problem and hearing

loss. She came here for physician of her son. After session she was sitting with her son in waiting room.



The researcher asked her that why she came here, she told that she comes here every week for session with her. She came to know about the speech problem when her son was two years old. She noticed that he does not respond well, he was not very attentive. He also could not speak. She became worried that why it's happening to him because her elder son started speaking within 2 years. The researcher asked question and respondent told her that she became worried and discussed this issue with her husband. Then they decided to consult a doctor. An audiologist confirmed that their son is having speech problem and also hearing loss. At that time she was shocked and extremely upset to know that her child is not like other normal children. From that day she became more caring for him. She regularly went for speech session and physician. Doctors told her that he cannot be normal but she was trying her

best to make him normal like other children as much as possible. The researcher asked about reasons of this deficiency. Mother of child told that they are not genetic because it was not before in her family. He did not cry at the time of birth, he also was suffering from jaundice, and doctors put him in ventilator for few days. The respondent said very sadly that “from the first moment he come to this world my innocent child is facing so many problems”.

However her husband was very cooperative; he did not make any difference between two children. He did not make her feel that our child is special. She felt hurt inside when she looks at a normal child. She took him along with her in gatherings but she felt really depressed, when she compared him with other children.

5.4.1 Education problems

Educating a special child is very demanding. As research found that for a child having any kind of disability it is difficult to fulfill his needs. Keeping in view due to these difficulties mostly parents are feared to send their children to school. She was searching for a school. She wanted to educate him. But he had attention problem and could not sit in the classroom.

Rehana, mother of Hassan was not adjusted in her husband’s house from the very first day. She was mother of 14 years old Hassaan. Hassan was suffering from mild mental retardation and was also physically handicapped.

5.5.1 Non cooperation of family

At the time of accident neighbors' help and family members also cooperate but gradually this burden is left only for parents and especially mothers. Whole family should take this responsibility to cope with this difficult situation but family members just look after few days for formality and after that only parents have to fulfill this responsibility.

Her in-laws behavior was not good with her. Every time they quarrel with her because her husband married her against the wish of his parents. When their first son was born he was disabled by one leg and also had eyesight problem. His parents did not know it at the time of his birth. Doctor also did not tell them.

The researcher asked that when she came to know about his disability. The respondent answered that she came to know when one day they were having dinner at dining table and her son asked her that give me glass of water and glass was in front of him. His mother told him that glass is in front of him, then he moved his hands (she said this by moving his hands to show me exactly that how his son was doing) on table just like blind people do and then she said "*mere paon k nechay se zameen nikal gai*" (became extremely shocked) then I came to know that he cannot see properly. Before this she also observed sometimes that he watched TV from very near but she did not

noticed much. This action made extremely upset then she visited doctor and he told her that he is having eyesight problem.

The respondent told about reasons that it was a result of her in laws attitude as they were not happy from her so they started doing magic on her. Her son was disabled due to effect of “kalajadoo” (black magic). Many times she found *taweez* (charm) in her room. Nobody can do this except my husband’s mother and sisters.

5.5.2 Family attitude

Accepting this bitter reality that newborn child is disable is very difficult. It becomes even more difficult for mother when she faces negative attitude from family. People make statements that your child is abnormal. They do not realize that child is not only of one woman (the mother) but he/she belongs to whole family. So, the research found that a special child is reason of stress, and depression for parents and whole family. A newborn baby is cause of happiness and joy for family but when they come to know that child is special, immediately reaction changes. Happiness turns to hopelessness and tension, especially when it’s a first child in the family.

Rehana was very much disappointed as her family members blamed her for the disability of her child. It was more depressing day for her when after three years another disable child was in her lap, her daughter. That day was the saddest day of her life. Her family members found another way to depress her.

She just felt helpless and could see darkness in her future life. She thought how she will survive in this situation having two special children. These children were burden on society and family. Which mother in the world wants her child to be disabled? She was fighting with her children's disability and was also facing problems. She was facing problems from her family. The respondent said that on that day she built courage in herself.

She decided to fight with all the problems bravely. She decided to make her children a productive member of the society. She struggled with them. She explained "I remember those days when I did not find time for myself even I did not have time to have meal as I was too much busy in taking care of my children".

The researcher gained her views about struggle and efforts regarding child. She told that her husband was abroad. She was alone, but today after long period of struggle she have made her children not exactly but to some extent that they are not a burden on the society. His son is disabled from one leg but she has educated him. He was working as cashier in "Ali medical pharmacy". It is just because of her individual efforts, no body helped her.

Talha was 7 years old child, he was studying in Nursery. He was disabled by one leg. He was the only son of her parents but unfortunately he has to live miserable life. He was in hospital with her mother; she told researcher that she lives in Gujranwala.

5.6.1 Role of family

The acceptance of child by the family is in fact helpful in molding the attitude of parents towards helping and managing the child more effectively. In Pakistan there is joint and extended family system and environment of home has direct effect on child development and grooming especially in the case of a special child. If cooperative family environment is provided it makes the child to cope in better position as compared to when he receives negative attitude of family members. Helplessness is inculcated in child due to attitude of parents, and parents' attitude is directly affected by attitude of family members. On the other hand these children are more vigorous who receive positive attitude of parents so they feel that their family is not rejecting them.

When she was expecting her husband was very happy, but unfortunately their son became disable by one leg. Her husband became very angry and his behavior changed immediately. He blamed her wife that her child is disabled.

5.6.2 Neglected child

Children are mostly disturbed when they are ignored or neglected. If one of the parents have negative attitude it makes life of child very difficult. Child needs attention of both parents.

He said "*betay to baap ka bazu hote hen lekin ye tumhara beta to mujh pe bojh ban gya sari zindagi k liaye*"(sons are supportive for fathers when they

become young they help their fathers but your son has become burden on me for whole life)".

5.6.3 Blame

Parenting a special child is a challenge for the whole family. Parents are especially more affected by this incident. The research found that due to birth of special child mothers are blamed. When a child is special most family members blame each other. This makes the situation even tenser.

The respondent explained that she requested her husband that it was not in her hands, neither was it my fault. She got divorce from her husband. Little child was in her lap and she was all alone in this world. Then she came to his brothers' house in Islamabad. Here also she faced many problems. The wife of his brother was cooperative at the start but gradually their attitude started changing. His brother was very kind. He helped her and supported her morally and also financially but she was living miserable life. She used to think that what was her sin that God gave her disabled child, and then she got divorced and now living like a prisoner in her brother's house.

5.6.4 Fear of future

Children are future of family as well as for the society. Although the research found that a special child is observed as a burden on society. Mostly parents have no plans for their future as compared to a normal child. Even they are not involved in family patterns.

The respondent explained that Talha went to school but he is very much problematic child for his mother and for his teachers as well. He shouts in class, he throws all things aggressively which teachers give him to play. He even threw food and water on his teachers. He also did the same at home, sometimes he also break things. Her mother told the researcher that she takes care of him and gives him a lot of time but it is not possible for her to keep eye on him all the time. She was feared about his future. She further told the researcher that she does not know how he will survive in future. His father does not support him anyway”.

5.7 Case No. 7

Hammad was 10 years old with eyesight problem .Hammad’s mother told the researcher, which he was born perfectly healthy and very beautiful. They were raising him just like normal children, but he started walking late as compared to other children but they took it as normal.



When he was 3 years old he hesitates to go outside with her mother or sometimes remain sitting at one place. He used to watch TV from very near.

5.7.1 Evil eye

Another perception is evil eye. They believe that their child become disabled because of the evil eye. In some cases parents believe that as their child was beautiful and healthy at the time of birth, therefore, the evil eye of some relatives or neighbor causes disability to their child.

When the researcher asked about the reason respondent told that her son was very beautiful and good looking. Also she was very clever. One day a neighbor came to my house and my son was playing. He was wearing beautiful clothes on that day. My neighbor admired my son and from that day he became ill.

5.7.2 Myth

The term myth is generally reserved for tales who are sacred or religious in nature, they are social rather than individual in their subject matter and concern with the origin or creation of some phenomenon which may be natural, supernatural or socio-cultural. While some believe that this disability is the will of God, it is fate, and nothing can be done to help these individuals.

She ignored this for many times but one day he fell while playing so this thing made me worried. She took him to doctor and he told her that your sons eyesight is very weak, and if precautions are not taken he can become blind for his whole life. At that time she became very much worried. This made him a special child. He hesitated to come in front of a new person. People said that he is a shy child, but actually he did not come because he could not see well. His parents could not afford to do his treatment, because doctors recommended surgery but it was very expensive.

Faizan is 10 years old boy, his one hand and one leg was damaged by polio when he was 6 years old.

5.8.1 Unawareness

The research found that most people are unaware of the fact that they have to take certain precautionary measures to avoid certain kind of illness or diseases in their children. It was observed after the child became a victim of disease. The parents think of precaution after the illness, but they are of no use at that

time. In this case child is vaccinated after polio attack but it was too late at that time. Unawareness and carelessness makes her whole life miserable along with her family.

His mother told that she was not aware of polio drops and was not expecting that she can be affected by Polio. After attacked of polio she took him to doctor. Doctor said that it is not curable now. She was very depressed to know that her son has to live like this whole life. It was their mistake that they were unaware of polio drops. If she gave her drops then her son does not have to live a disabled life.

5.8.2 Poverty

In poor families parents have 9-13 children so they do not care their disabled child. Economic factor is a basic barrier in their studies and in adjustment. Here we can say that poverty further aggravates the situation and leads to more dangerous and unfavorable condition for the disabled child. Due to economic crisis parents cannot provide appropriate care to their disabled child as they deserve.

She further told the researcher that she advised her husband to take Faizan to some good hospital for complete check-up. She used word "*bara haspatal*" (good hospital). However due to lack of resources they could not provided him a proper treatment. She knew now any type of treatment will not work. She wanted to get some hope. Due to poverty and lack of resources they could not afford to go to the hospital. They just visited local doctor and he said that

their child is affected by polio. She further said that, she wanted him to be normal but when he walks with the help of crutches my heart cries. She wished to give her own legs to her son, she said pain fully.

5.8.3 Isolation

A disabled child is totally isolated from the society; he is labeled as a disable person. He might have extra efforts as compared to normal children but he is not given a chance to show his efforts. He gets treated as useless member of society.

The respondent explained “most hurting moments are those, when other children are playing but her son sits far away and see them with hopelessness.” He likes to play cricket but unfortunately he cannot. She said that when he walks with the help of crutches people sometimes call him “*Langra*”.

5.8.4 New social identity

People have a conception that disabled person lack the ability to lead a normal life. They are excluded from normal daily routine life and are perceived as burden on parent’s shoulders for the whole life. The research found that disable individual does not have to fight with their disability rather they also have to face a new social identity which is given to them by society, in the forms of terms that directly referred to handicapped. An individual first living in a society as normal individual but immediately he has to settle himself with

a new social identity. It is difficult to accept this new identity. It is depicting the behavior of society towards special children which is unfortunately discouraging. First an individual is normal and he had different school, teachers, and friends but after incident or disability he is not able to adjust with old friends and new ones is not ready to be his friends.

The respondent told that He was studying in the school with normal children but because of his disability, he became very sensitive. One teacher called him *langra* instead of his name and he refused to go to school. At that day he came home and threw his bag on the floor and said, "I will study at home but I will never go to school".

5.8.5 Adjustment barrier

Lack of awareness is major barrier especially in the cases of incidentally handicapped children. Before this they were leading normal life but after an unexpected incident their role in society immediately changes and a stigma of disable are attached with them.

He also left going outside because children used to tease and disturb him. She further said that, "we are poor people and could not afford much expense."

Usman is the only brother of his two sisters. He was mentally retarded 8 years old boy. He came with his mother for session. He was over active and aggressive boy. He was not letting her mother to sit at one place. He was running here and there and also disturbing other people which were sitting around. Then she tied him with chair, he was still moving and trying to open himself. His father was a poor man and could not afford the expenses of his treatment. After his birth as disabled, his father became careless for all family members. Usman's mother further told me, that she worked in different houses to fulfill the needs of children. When Usman was born all of them were happy. Although when doctors told me that he is mental and disable it was shocking for us.

5.9.1 Impact of conservative mind

In Pakistani society family structure and bondage is very important factor. Elders of the house like Grandfather and Grandmother have more impact on the entire house environment. Their thinking has strong impact on decision making. Special child is viewed sometimes as a curse in the sense that elders say that our forefathers have committed some sins so we are facing punishment of their sins in the form of this child. This makes the child totally indifferent member of the family. In some families whole decision making power is in the hands of grandparents. It is advanced to some extent but in this era everyone has to struggle to become productive member of society, conservative thinking hides the abilities of children.

She further said that she went to many shrines and done many methods to make him normal. She has tried a lot of methods to heal her. When the researcher asked about which type of methods, she said that her son always secrete saliva from his mouth. Then His Grandmother advised her to make a “roti” (an eatable made by flour) and touch it with her son lips. And let some dog to eat this. Then your son will be cured. His condition is becoming worse and worse as he is growing up. When she went for work, tie him with cloth with chair or bed, so he cannot move. I could not leave him alone at home. When some time he got free, touching everything even switches of electricity. She said, he is not able to go to school. His mother also could not participate in any gatherings along with him.

When his father came back home, does not look towards him. Attitude of his father is very discouraging for me as well as for my children. This attitude of his father took her in more trouble.

Sheeraz naeem is a 12 years old boy. He is mentally and physically disable. He lives in joint family system and his mother is housewife. Sheeraz lives in G10 with his family. He lives inside the house all day. His mother told that it is very difficult to look after a disable child but now she is trained. When he was born they did not know that he would be disabled. Doctors also did not tell them that he will be abnormal. She came to know when he was 3 months old. Her sister was of same age and she started movements like a normal child

but her son did not. Her daughter moved her head, but Sheeraz could not. At that time I came to know that her son is disabled. After two months, Sheeraz got severe fever and his mother took him to the doctor. He told us that their child is not normal. I told him that at time of his birth doctors did not tell us. His disability is by birth. His disability is due to cousin marriage. There were also two other children disabled in her family. And they were not aware before. After knowing this now they decided not to marry within the family. My reaction at that time was very much depressing. With the passage of time she got patience. Whether she wanted or not but she had to show patience because there was no other solution. She further said that still there are some occasions on, which she felt that what has happened to us. Her son is mentally as well as physically disable. When it comes to family support her husband supported her a lot. Family members also supported, whenever she needed to go somewhere. She wanted him to study and sent him to special school. But he did not adjust himself there. When he came back from school he used to say that he will not go to school. No one is my friend there. Actually children there were suffering from severe retardation, but my son was not severe retarded. That is why he could not adjust there. So he left going to school. When he started going to school I thought that he will be able enough to fulfill his responsibilities, but unfortunately education was also not in his fate. His mother said "for his future now I just pray that he die before us, because after

us who will look after him”. I also wish that may Allah give us more courage to bring him up.”

Allah hamara saya in iske sar pe qaimr akhay” (May Allah keep us alive for them ever).

5.10.1 Punishment of sins

Mostly it is perceived as punishment of sins. Parents think and also it’s a general view that our grandparents or parents have committed some sins so Allah has punished us in this way and make our child a punishment for our whole life.

Sheeraz’s mother said; whenever I took him outside people ask very strange questions. Sometimes they show pity. I feel hurt when some people say that his abnormality is due to my sins. They say that some curse is following us. It is very difficult for me to answer these questions of people.

5.10.2 Socio cultural factors responsible formal adjustment of disables

The disable carry the burden of many social disadvantages such as

Feelings of inferiority complex,

Fear of social embarrassment.

Inability to compete with physically able bodied people.

Lack of will and self confidence.

Restricted morality in interacting with social situations.

5.10.3 Customary determinants of disabilities and cultural cognition of people about disabilities

It is claimed that peasant or traditional societies are characterized by fatalistic attitude towards life, in other words, members regard their own action as powerless to influence the course of events.

Different geographical regions and different historical moments may be characterized by a variety of prevailing attitudes and we should perhaps regard fatalism not as an absolute value of peasant society, But rather as one of set of traditional attitudes which may come to fore under various circumstances. Despite of traditional settings even in Islamabad the capital city, people possess different sort of myths and fatalistic ideas that are responsible for the disability of their children.

Chapter No. 6

DISCUSSION AND CONCLUSION

Present sociological study was conducted in N.I.R.M located in sector G-8/2, Islamabad, capital of Islamic republic of Pakistan. The topic on which present study focused was “Perceptions of parents about special children needs”. The study focused on problems faced by disable or special children in society

Main areas of study were perception of parents, family members about exceptionality of child. The main source of data collection was interview guide and participant observation and photographic techniques in some cases. Parents perceive child with disability, mental retardation as a person with delayed development. Concept of causes is better understood by parents as compared to other family members. Every parent knew more or less about causes. There was also some interference of myths and superstitions especially when it comes to cure. Parents do possess different attitudes towards the disabled child. Mostly mothers had high favorable attitude as compared to fathers, and these mothers also concerned with solving the problems of their child, they care for admitting their child to school. Expectations related to child's overall development are also higher in parents than in other family members. Child's ability to fulfill responsibilities of life has been doubted by parents. It appears that child would need support and guidance throughout his life. Problems encountered by family due to child's disability were mainly changes in family patterns, emotional pressures, increase in responsibility and worries for child future. Major problems regarding education and care of child reveals parents unawareness of skills involved in working with mentally retarded children. The determination of level of education for child was related to child's limitation by some of the parents while others desired the child to achieve higher education.

Suggestions

Knowledge related to disability may be developed among people by providing knowledge of concept, classification, causes and possible interventions and strategies to parents and siblings of disabled children.

Media can play important role in spreading awareness about knowledge related to disability parents meetings and interactions should be arranged in order to make parents to discuss problems with each other and finding solutions.

Family members should be informed about child's strengths and weaknesses; it will help them to attach realistic expectations with child relating to education, occupation and marriage.

Only parents are not made responsible for caring of child, to achieve maximum progress all family members should be encouraged by professionals.

Special children require special care and equipment also; poor families are not able to fulfill demands of their special child so financial support must be provided to needy families by government and volunteer agencies.

Special children should be made to participate more and more in social gatherings and special recreational activities must be arranged for them.

Possibilities of job oriented training should be provided for growing disabled children. Arrangements of job settlements should be considered important at macro level.

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