Effects of Child[illegible] with Intellectual Disability on Families in Khyber Pakhtunkhwa, Pakistan

Submitted By:

SHAKEEL AHMED
PhD Scholar (Social Work)

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VIVA VOCE COMMITTEE

SUPERVISOR:

Prof. Johar Ali (PhD Hull)
Department of Sociology
University of Peshawar

CO-SUPERVISOR:

Dr. Noor Sanauddin (PhD Glasgow)
Assistant Professor
Department of Sociology
University of Peshawar

EXTERNAL EXAMINER:

Dr. Sadia Saeed
Assistant Professor (Social Work)
Department of Social Work
University of Peshawar

COUNTERSIGHED BY:

Prof. Rashid Khan
Chairman, Department of Social Work
University of Peshawar

26.1.17.

Dedication

Dedicated to brave mothers and care-givers of intellectually disable children in Khyber Pakhtunkhwa, Pakistan.

ABSTRACT

This study explores the effects of children with Intellectual Disability (ID) on families in Khyber Pakhtunkhwa (KP), Pakistan. A total of 58 parents were interviewed by employing qualitative data collection techniques such as In-depth Individual and Focus Group Interviews in four districts (i.e. *Peshawar, Nowshera, Mardan* and *Haripur*). In addition, 15 officials of the special education centres were also interviewed for exploring institutional role in mitigating miseries of affected families.

This study shows that environmental barrier and negative attitudes towards child with ID imposes adverse effects on families which vary from family to family. For instance, nuclear families were seriously affected than joint families owing to limited family members and lack of social-economic support. Subsequently, the functions (socialization), social organizations, (re) production, stability, reputation, authority, socio-emotional security of the nuclear families were seriously disturbed. On the other hand, joint families were found least affected due to socio-economic support of family members. However, social reputation of joint families was affected due to stigma associated with ID. Mothers in the nuclear families were badly affected as compared to fathers due to patriarchal structure and poor institutional support. Subsequently, they faced social exclusion, social stigma and taunt, strain relations with spouse, and their non-disable children. Unlike mothers, fathers were affected less, yet as guardians and breadwinners' fathers face financial burden in fulfilling the 'special needs' of intellectually challenged children. Such extra financial burden also affected the educational, medical, and nutritional needs of the non-disable children.

By employing 'social model of disability', patriarchy, lack of education and lack of government interest in recognizing ID as a serious disability, were the major barrier that had crippled families in dealing with such children. Moreover, the indifferent attitude of government made the institutions of special education and social welfare ineffective; consequently, these institutions failed to mitigate the miseries of such families.

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ABBREVATIONS AND ACRONYMS

AAIDD	American Association on Intellectual and Developmental Disabilities
AAMR	American Association on Mental Retardation
ADB	Annual Development Budget
ADB	Asian Development Bank
ARC	Autism Resource Centre
APA	American Psychiatric Association
ASRB	Advance Studies Research Board
CRC	Child Rights Convention
CBR	Community Based Rehabilitation
DAAD	German Academic Exchange Service
DSM	Diagnostic and Statistical Manual of Mental Disorders
CID	Child with Intellectual Disabilities
DGSE	Federal Directorate General of Special Education
GDP	Gross Domestic Product
FBS	Federal Bureau of Statistics
FBISE	Federal Board of Intermediate and Secondary Education
FGD	Focus Group Discussion
GoP	Government of Pakistan
ID	Intellectual Disability
IDI	In-depth Interviews
ICT	Islamabad Capital Territory
IQ	Intelligence Quotient
IASSID	International Association for the Scientific Study of Intellectual Disabilities
ICIDH	International Classification of Impairment, Disability and Handicapped
PCPID	President's Committee for People with Intellectual Disabilities
ILO	International Labour Organizations
KP	Khyber Pakhtunkhwa
PKU	Phenylketonuria
MR	Mental Retardation
MDGs	Millennium Development Goals
MR & PH	Mentally Retarded and Physically Handicapped

NGOs	Non-Governmental Organizations
N.W.F.P	North West Frontier Province
NTCSP	National Training Centre for Special Persons
NPPD	United Nations International Year of Persons with Disabilities
NCHD	National Commission for Human Development
NISE	National Institute of Special Education
PSWC	Provincial Social Welfare Council
PCRDP	Provincial Council for Rehabilitation of disable persons
PCCWD	Provincial Commission for Child Welfare and Development
P & D	Planning and Development
PWD	Person with Disability
UNICEF	United Nations Children Fund
UPIAS	Union of the Physically Impaired Against Segregation
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
UN-ESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNDP	United Nation Development Programme
UN	United Nations
UK	United Kingdom
VHC	Visually and Hearing Impaired Children
WHO	World Health Organizations
WHO ICD	World Health Organization's International Classification of Diseases

CHAPTER 01 INTRODUCTION

This study explores the effects of children with Intellectual Disability (ID) on families in the province of Khyber Pakhtunkhwa, Pakistan. Intellectual Disability refers to "the substantial restrictions both in intellectual functioning and in adaptive behaviour, as articulated in conceptual, social, and practically adaptive skills" (Schalock, *et. al.*, 2007: 116). For most families in Pakistan, it is more suitable to conceal intellectual disability owing to the fear of stigma (Ahmed, 1995). Families realize the damages when a child almost reaches the age of eighteen. Then the families encounter with economic, emotional and psychological problems due to the extra care of such children associated with negative attitude and institutional barriers (Jamison, 1965; Boyd, 2011; Gohel, 2011; Cohen, 2011).

To explore such effects, data was collected from the parent and officials of the institutes related to rehabilitation of children with ID. A total of 58 parents were interviewed, out of whom 30 parents were selected purposively from the list of institutes located in district *Peshawar* and *Haripur* (15 parents from each district). In-depth interviews were conducted with them. Along with individual interviews, 4 Focus Group Discussions (7 participants in each FGD) were also conducted with parents for getting more valid and reliable information. Similarly, to explore the role of institutes in mitigation of miseries of parents, officials of the concerned institutes were also interviewed. For this purpose, 15 in-depth interviews were conducted with officials selected from the five institutes located in four districts of Khyber Pakhtunkhwa i.e. from *Peshawar*, *Nowshehra*, *Mardan* and *Haripur*. A qualitative methodology based on the interpretivist-phenomenology was adopted for the study.

This study shows that indifferent attitude of society regarding children with ID did not impact all families in similar ways; rather family structure i.e. nuclear and joint

families determined the adverse effects on family life. Nuclear family here refers to system social ties between parents and their children while joint family refers to a system of relation among parent, children and other kin.

Within families, parents, especially mothers in nuclear families borne social effects such as social exclusion, strained spousal relation, extra fatigue for working women, family displacements, and taunting and sarcastic remarks from society. Such adversities were due to patriarchal construct of society wherein woman performed multiple roles in the household chores without appreciation and recognition. Moreover, the study found that due to the multiple roles such mothers faces psychological effects such fear of stigma, chronic stress, and depression. However, such adversities were borne by fathers being the bread-earners for their families in families in Pakistan. Furthermore, economic effects such as enhanced family expenditure affected the family resources and needs of the non-disable children as well.

These effects, subsequently, disturbed the function (socialization), social organization, (re) production, stability, reputation, authority, socio-emotional security of the nuclear families. On the other hand, mothers and fathers of children with ID in joint families were least affected due strong social support. Hence, it has not affected the social organization, production, stability, participation, social and emotional security of joint families. However, reputation of the family were badly affected due the birth of such children.

After a thorough analysis with the lens of 'Social Model of Disability' and the primary data, as reflected in chapter 7, it was found that such affects were primarily due to the patriarchal structure of society, low literacy/awareness regarding psychological and mental health problems and poor welfarization in the province. Furthermore, the institutions' role was also analysed and hence, it was found that institutional role was

least effective in training and rehabilitation of such children due to lack of an effective policy, shortage of funds, lack of job structures, shortage of modern devices, and trained staff. The major reason of this ineffective role was poor welfarization in the country in general and the province in particular. Research finding support the social model of disability which says that social and institutional barriers make a person and their family disable, otherwise, they can live life like other human being.

1.1. My Motivation for Conducting this Study

It is important to share that how and why I decided to go for this topic. My first interest and motivation in the area of disability and special education developed during my first ever field training in my post-graduation at the Department of Social Work in 1998. During field work, I had interaction with the family members and parents of children with disabilities. During interviews and discussion sessions with parents and family members, I was highly intrigued by their views and experiences. Hence, that was one reason which motivated me for this research.

Afterwards, I got an opportunity to work as a researcher in a study on "The Status of Female Children with Special Needs in Rural Areas of District *Peshawar*". The findings of the study were published as my first ever research paper and the work was also presented in a "National Conference on Status of Children with Special Needs in Pakistan" in *Peshawar* which was organized by Strathclyde University, Glasgow, UK and British Council, *Peshawar*. These reflections and experiences further motivated me to think over the issue of disability.

After completion of my PhD course work, I was encountered with the selection of topic for research. Hence, I selected a topic with the title "Evaluation of Special Education Services for Children with Disability in Khyber Pakhtunkhwa", under the supervision of Professor Sarah Safdar (Department of Social Work, University of

Peshawar) for which she suggested 550 sample size. I felt happy and was very enthusiastic about the topic and such gigantic sample size, I was supposed to collect. With the passage of time, when I used to share the topic with relevant people, they would give a very normal response. For instance, once during discussion with my teacher Prof. Dr. Amir Zada, he responded that the area had already been studied by many researchers. Interestingly, during this state of confusion, I received a notification from University of Peshawar about a training workshop on 'Effective Synopsis Writing' which was organized by German Academic Exchange Service (DAAD) at Quaid-e-Azam University, Islamabad for a period of three days. Hence, I submitted my application with synopsis which was selected. In the training, every participant had to present his/her synopsis to German Professors who would guide and assist the scholars in finalization of their synopsis. I was placed in the group of a renowned anthropologist who was the author of five books and more than 50 articles in the field of qualitative research. During the training orientation, she asked me "what do you want to achieve from such a huge sample size of 550?" She finally suggested that I should revisit my approach and focus on my research topic and if possible squeeze the sampling size to 30 to 50 cases. I was very embarrassed, however, after finishing the event, when I shared my experiences with my supervisor, she was not willing to squeeze it as she was trained in quantitative research methods, and hence, I decided to change my supervisor. Luckily, I discussed the matter with Professor Johar Ali who was specialized in qualitative research and he accepted my request for supervision, hence, I started my research journey with him; however, he advised me for an extensive review of literature for the selection of my research topic.

Hence, I started collecting and reading books, articles and newspapers related to the area of disability. During this stage of search, I once accompanied students of social

work to the Special Education Centre at *Bashir Abad* as an orientation visit before the start of their field work, where I asked a case worker about the problems of children with different disabilities enrolled in the centers. He responded that children with intellectual disability constitute the most difficult segments in the centre. Parents of mentally retarded (MR) children suffer a lot. I asked about the cause and nature of MR. After listening to him narrating the miseries of parents, I was motivated to start thinking about the problem. My motivation was converted into my interest. During this journey of thinking and observation, I came across a family which had two children of age 5 and 2 years with Intellectual Disability. Observing the agonies and pain of the family members, I had made my mind to analytically understand the pain and effects of such children on the family.

After selection of the topic, while conducting the literature review, I found that only a single study had been carried out on such an important issue so far titled as "The Causes of Mental Retardation: A Comparative Study of Khyber Pakhtunkhwa and Balochistan" (Zaman, 1996). Whereas a dearth of literature on the psychological aspects of the issue was encountered, the sociological aspect had hardly been explored.

1.2. Objectives of the Study

The following objective were set for the study.

- To explore the socio-economic and psychological effects caused by social attitude on families having children with intellectual disability.
- To explore and interpret views, feelings, perceptions, and experiences of parents about their children with intellectual disability.
- To know about the efficacy of the facilities extended by the government to mitigate families' sufferings from the problems.

1.3. Significance of the Study:

This study is a first ever effort with respect to intellectual disability in Pakistan as no such empirical research with focus on sociological perspective (Social Model of Disability) has been conducted. This study reflected upon the effects of children with intellectual disability on families and institutional role in mitigation of parent's miseries. Indeed, other scholars and researchers from the field of psychology have conducted researches on intellectual disability in Pakistan but their focus had always been limited to psychological dimensions such as emotional impact, anxiety and depression among the care giver (see Inam and Zehra, 2012). Only a single PhD study in the field of Social Work had been conducted (Zaman, 1996) with focus on the causes of ID. Moreover, previous studies have focused on causes and IQ tests in isolation and unable to see the sociological dimension of the problem. Therefore, this study is significant not only starting effort in the province rather a knowledge addition disability studies in Pakistan. Similarly, other such studies have been conducted either in American (see Irma, 1987) or in Africa (see Pilusa, 2006) but these studies lack diversity, hence, such studies could not be generalized to other societies such as Pakistan. Different researchers recommended broader studies with a focus on sociological perspective in their studies (see Irma, 1987: 66; Pilusa, 2006). Moreover, diversity based approaches to researches have also been recommended by Booth (1994), Edwards (1994), and Hulme (1994). Hence, this study is an attempt to develop diversity-based knowledge which could reflect the genuine problem of a particular society.

1.4. An Overview of Research Process

This study aims to empirically explore socio-economic and psychological effects on families caused by negative attitude towards child with intellectual disability in Khyber Pakhtunkhwa. In other words, it aimed to explore the extent to which the issue

members such as parents and other close family members and care-givers. Moreover, it also examined the role of institutions such as special education schools and centres in mitigation of miseries of parents and other family members by providing effective services to the child and counseling services to the parents. At the initial stage, it was understood that the issue under discussion is quite straight forward. Therefore, I focused on assessing the problems of parents by asking simple questions. Nonetheless, it was discovered in the field that the ID is not as simple as the effects were embedded with the socio-cultural factors such as patriarchy and lack of indigenous mode of social welfare in the country in remedying the problems of affected parents.

The manifestation of these factors caused me to become quite curious about the deep-rooted causes of such effects. As a result, my focus was modified and shifted from simple questions to a more critical and theoretical analysis of effects on the families. Thereafter, while juxtaposing the empirical data with secondary data and personal observation, I thoroughly analysed the socio-economic and cultural effects in relation to the institutional roles, such as assessment, counseling, therapies, parental counseling, and provision of rehabilitative training to such children.

A thorough analysis led me to the deep-rooted causes of such effects and the institutional role in mitigating such miseries. The analysis suggested that the imported model of social welfare and special education is not feasible in rehabilitation of such children and mitigation of miseries of their parents because of its incompatibility with social structures and values of our society.

The poor role of the institutes was explored from the views and experiences of staff members of the respective institutes. The findings were consistent with the review of literature (see chapter II) which reflected that children with intellectual disabilities face challenges due the indifferent attitude of society. The attitude of Pakistan's

face challenges due the indifferent attitude of society. The attitude of Pakistan's government was also found to be indifferent in taking up this issue. On the one hand, family institution is losing its traditional social support due to transformation of family structure from joint to nuclear structure owing to various social and economic factors. On the other hand, traditional approaches to the support of destitute and poor through the institution of *zakat* and other charities were fitted into bureaucratic and political framework, hence, it has lost its impact and people give such charities informally which are least effective in solving the problems of affected families and children in the long term. The social welfare and special education directorate of the government has become fleshless bones which is struggling for its own survival, hence, far from being able to mitigate the miseries of parents.

1.5. Synopsis of the study

This thesis consists of eight chapters. The chapter 1 presented an introduction to the thesis, chapter 2 reviews already done researches and discusses the concepts of disability, intellectual disability, and special education in Pakistan and Khyber Pakhtunkhwa. This chapter also review various theories of disability in relation to the prevalence of disability with reference to its causes. The description of the theories brings to the surface not only their prevalence in different societies but also how people with disabilities are and have been treated in different times and places.

Chapter 3 describes social welfare and special education in Pakistan and Khyber Pakhtunkhwa. It reflects on the concept of social welfare with special focus on theoretical explanation and discusses the historical development of social welfare in Pakistan. It finally sheds light on the causes of poor welfarization in Pakistan in general and in Khyber Pakhtunkhwa in particular. Chapter 4 describes the entire research process and methodology followed in this study.

Chapters 5 & 6 presents the substantial part of this thesis in the form of primary data. Chapter 5 consists of parents' perspective on IDs. It explores how parents feel about their child with ID. Chapter 6, presents the Officials' perspective of Social Welfare Department regarding the status of services for children with ID.

Chapter 7 analyzes the primary data presented in Chapters 5 & 6 and compares it to the existing literature presented in Chapter 2 & 3. It is composed of two parts. Part I describes why intellectual disability of children negatively affects families, parents, mothers, and other family members?. The effects have been linked with deep-rooted causes which were supported by theories as well and presented a logical analysis to the problem. Part II explains the reasons of failure of social welfare sector and special education in mitigation of parents' agonies. The reasons of poor welfarization were supported by theoretical explanation.

Chapter 8 concludes discussion and draw a conclusion from the already discussed primary and secondary data. It also revisit chapter 2 in order to authenticate the result of the study in the light of already existed knowledge and work. It also summarize research findings related to effects on the family and explains in detail the institutional role in lessening the agonies of the parents and dealing with such children effectively in a society. The last section of the chapter highlights the implication of the study for the future researchers.

CHAPTER 02 THEORIZING DISABILITY AND INTELLECTUAL DISABILITY (ID)

This chapter briefly reviews the concept of disability followed by a detailed discussion on Intellectual Disability (ID), including its causes, theories, and effects on society and family. The chapter consists of five parts. Part I is concerned with explaining the concept of disability in general. Part II explains intellectual disability in detail, including its various causes and types, along with a critical discussion on the rationale of terminological shift from mental retardation to intellectual disability. It also presents a picture of prevalence of intellectual disability in the world in general and in Pakistan in particular to gauge the severity of the issue. Part III of this chapter discusses the various ways in which a child with ID affects family members. It covers the different social, psychological and financial problems faced by family members while rearing and taking care of an intellectually disable child. Part IV of this chapter discusses the various theoretical debates and perspectives concerning intellectual disability. The last part, i.e. Part V revisits the literature and identifies gaps and lacunas which the present research intends to fulfill.

2.1. The Concept of Disability

The issue of disability has recently been a topic of critical debate for the social scientists, disability advocates, and policy makers throughout the world. Such debates started in 1976 at the United Kingdom (UK) by an advocacy group composed of individuals with disabilities who founded the Union of the Physically Impaired Against Segregation (UPIAS) and laid the foundation of the British Disability Rights Movement which is also known as "Fundamental Principles of Disability". The most important contribution of this debate to disability study is the proclamation that "it is society which disables physically impaired people" (Frank, 1984: 43). Before this movement,

disability was thought as ''private problem of unfortunate families and their individual members' (Ibid). Moreover, disability was considered as a marginalized field of study for sociologists and anthropologists, by viewing disable as inherited amputee (Frank, 1984) and were discriminated as the other somehow separate from people who were not considered to have disabilities (Ablon, 1995). Consequently, many people with disabilities experience exclusion from everyday life activities and services such as health care, education, and employment opportunities. However, after the advent of the disability rights movement, the issue of disability was brought to the forefront of national attention and received the interest of social scientists, medical practitioners, and academicians (Edgerton, 1967, 1984, 1993).

Hence, this struggles laid the foundation for a framework known as the social model of disability which proposed that it is mainly society's failure to consider the needs of persons with disabilities in designing a favorable social environment due to which people with disability are unable to play an active role in society (Oliver, 1990).

Moreover, the advocates of disability rights claimed that "disability is something imposed on top of their impairments by the way they are unnecessarily isolated and excluded from full participation in society which makes them a socially oppressed group" (Union of the Physically Impaired Against Segregation (UPIAS), 1976:3–4). In the United States, the new perspective on disability, known as social construction of disability, is reflected in civil rights and political framework (Mayerson, 1993).

Resultantly, mainstreaming disability into international development policy and local development has become a greater priority for the disability right movements and various developmental organizations. It is getting recognition as a major change to ensure that people with disabilities all over the world receive the same rights as any other citizen. The introduction of the UN Convention on the Rights of Persons with

Disabilities (CRPD) played a great role in improving the status of persons with disability in the world (UN Report- CRPD, 2006).

2.2. Definition of Disability

Before the Disability Rights Movement, most of the definitions of disability were restricted to physical disability. For example, the following definition overly focuses on physical impairment:

> "The loss or abnormality of psychological, physiological, or anatomical structure or function" (Susman, 1994: 15).

However, the policy shift of United Nations due to Disability Rights Movements has impacted the conceptual clarity of the disability and has developed the following holistic definition of disability:

> "Long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [a person's] full and effective participation in society on an equal basis with others" (UNCRP, 2006: 1).

This definition focuses both physical and mental aspects of disability. Even more importantly, the definition recognizes the importance of social interaction and societal barrier which further isolates a disable person. These social barriers are considered major hindrances in mainstreaming of a person with disability. A person with disability can reach the epic of development in any field provided if he/she is supported with required needs. The well-known case of a prominent Professor of Astrophysics, Stephen Hawking who is suffering from Motor Neuron Disability, is a case in point. In his own words:

> "Disability need not be an obstacle to success. I have had motor neuron disease for practically all my adult life. Yet it has not prevented me from having a prominent career in astrophysics and a happy family life..... (Hawking, 2011: IX)."

He further said that:

> "...I rely on a team of personal assistants who make it possible for me to live and work in comfort and dignity. My house and my workplace have been made accessible for me..... (Hawking, 2011: IX)."

As this testimony for the world's most well-known disable person shows, disability does not automatically exclude a person from being a well-integrated member of society. Proper care and assistance from family and society can enable a disable person to live a happy and productive life.

2.3. Prevalence of Disability

It is normally believed that the number of people with disability is increasing day by day in the world in general and in Pakistan in particular due to various socio-economic reasons. According to World Health Organization (WHO) there are more than one billion people in the world which constitute around 15% of the world's population (World Report on Disability, 2011). Such people live with some form of disability among which nearly 200 million experience considerable difficulties in functioning (World Report on Disability, 2011). Out of 200 million, 80 million (82%) people with disability are living in developing countries.

Persons with disabilities are facing multiple challenges and the most alarming one is their exclusion from mainstream development agendas due to disability and lack of economic opportunity. Similarly, among the world's poorest, 20% persons live in absolute poverty and has some kind of physical impairment. Beside economic hurdles, people with disabilities have poorer health outcomes and lower education achievements as compared to non-disable people in the world. Moreover, such population is mostly deprived of social welfare services in the world in general and in developing countries in particular (WHO, 2011).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) considers disability as a human rights issue due to the evidence that persons

with disabilities are facing worse socio-economic consequences and poverty as compared to non-disable people (WHO, 2011).

The developing world, as referred above, has the highest prevalence rate of disability, however, in term of moderate and severe disability, South-East Asian regions have the second highest occurrence rate of moderate disability (WHO, 2013).

In the absence of regular Census in Pakistan, only approximate or projected numbers of disable people in the country is available, according to which 2.49% of the country's population is suffering from some form of disability. This constitutes 5.035 million people (Government of Pakistan, 2002) which is more than the population of Norway, New Zealand, Lebanon and Kuwait (Waqar, 2014). Similarly, the current annual growth rate of disabilities is 2.65%, greater than the population growth rate (2.03%) of Pakistan. Out of the total disable population in the country, only14 percent are employed in the market. It is evident that 86% of the disable population in the country falls under dependent category (Waqar, 2014).

The children with disability population in Pakistan is 43.4% of total disable population. Male and female child disability is 58.4% and 41.6% respectfully (Population Census, 1998). Similarly, according to the reports of Government of Khyber Pakhtunkhwa (2008), 6% of children between the ages of two and nine have at least one type of disability such as unable to do any productive activity due to their inability to see, hear, move, speak and learn. Among such children with disability, around 26% of children who are two years old are unable to name at least one object (Government of Pakistan, 1998). About 1.4 million children of school going age have no access to education (i.e., 28.9% of total PWDs population).

Despite the substantial number of people with disability in Pakistan, disability is normally considered a non-issue in Pakistan. Consequently, they are mostly neglected segment in society as they are not reflected in policies nor in the media. PWDs face

numerous barriers owing to stigmatization. Their aspirations are most often misunderstood. Beside socio-economic hurdles, the delay in official census (last one in 1998) creates problems of data as there is a scarcity of informational data. The 1981 International Year of Persons with Disabilities marked the beginning of international recognition of PWDs. As a result of this, 1980s saw numerous steps for disable being taken in Pakistan and around the world (Government of Pakistan, 2002). In Islamabad, the Federal Government established a Directorate General for Special Education. Likewise, many centers for rehabilitation of disable persons were also established around the country.

The first decade of the 21st Century brought numerous good news for disability. The National Policy for persons with disability was formulated in 2002 which is called as 'the National Policy for Special Education, 2002'. This was a milestone in the field of disability and recognizing the status of PWD. In 2005, the United Nations adopted a new convention on disability known as UN Convention on the Rights of Persons with Disability. The Government of Pakistan ratified the same convention on 5th July, 2011 (Isa, 2012).

2.4. The Concept of Intellectual Disability (ID)

Now that we have defined and explained disability, it is important to define and understand intellectual disability. The following section, therefore, first defines intellectual disability, and then critically reviews the debates on using appropriate terminology for different kinds of disabilities and their importance. After this, the section presents the various types / levels of intellectual disability as well as its causative factors. Lastly, the section discusses some of the impacts of ID on children.

2.5. Definition of Intellectual Disability

It is difficult to understand the nature of ID and lives of persons with ID without a clear and universally accepted definition (Ziegler *et. al.,* 1984). The importance of a distinctive name or definition is extremely necessary as elaborated by a Chines Proverb that: '*wisdom begins by calling things by their right name'* (Schroeder, Gerry; Gertz and Velasquez, 2002: 5)".

According to The American Association for Mental Retardation (2002: 1), "ID is a particular state of functioning that begins in childhood and characterized by limitation in both intelligence and adaptive skills".

There was a time when people with ID were labelled as lunatics or were considered as 'human vegetables' which referred to a condition of chronic sickness which is difficult to recover (Laureys, *et. al.*, 2010).

Besides issues with defining ID, the term was also associated with odd terminologies in the past such as "idiocy, feeblemindedness, mental deficiency, mental disability, mental handicap, and mental subnormality" (Goodey, 2005). However, Edergton, LIloyd and Cole (1979:4) have explained ID in clinical and sociocultural perspectives. According to clinical perspective, ID can usually be related with physical deformity, neurological and metabolic disorders while sociocultural perspective postulates that such children are mostly born in families who are economically, socially and educationally deprived. This perspective relate Intellectual Disability/Mental Retardation with maladaptive behavior (Rapley, 2004). Consequently, the diagnosis of such disability is determined on the basis of this perspective which assess behavior and actions of the child rather than intellectual deficiencies.

On the other side, IQ tests are generally considered as another way of diagnosis of such disability. For instance, "*a person with IQ of 70 to 84 are placed on the*

borderline of ID" (Gates and Barr, 2009: 6). Similarly, those who have IQ 55 to 69 or upper are called mild retardation (Ibid). Mild retardation usually involves a reasonably well adapted behavior. It is owing to this reason that some does include mild retardation into the definition of retardation (Rapley, 2004). Likewise, the term idiot was used for someone who have IQ lower than 30 while "imbecile" who had an I.Q around 30 to 50, and a moron an IQ of 50 to 70. Later on, terms idiocy, imbecile, and moron was replaced in the English-speaking world by the American Association on Mental Disability (AAMD) with these categories: mild retardation (IQ 55-69), moderate retardation (IQ 40-54), sever retardation (IQ 25-39), and profound retardation (IQ less than 25) (Edgerton, Lloyd and Cole, 1979; Rapley, 2004).

Furthermore, DSM IV (American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Version IV, 1994) defines ID as developmental condition that is characterized by significantly lower than average level of general intellectual functioning. Hence, intellectual functioning must be escorted by shortfalls in adaptive behavior such as "communication, self-care, education, work, leisure time, and health" (Schalock *et. al.*, 2007:116), which fall in age related functioning. Resultantly, this dual-criterion approach emphasizes on shortfalls in both social functioning and mental abilities which was initiated by AAIDD i.e. the American Association on Intellectual and Developmental Disabilities. Hence, ID is a disability "characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practically adaptive skills which originate before age 18" (Luckasson, 2002: 1).

2.6. Terminology Debate: Intellectual Disability Instead of Mental Retardation

There is an ongoing debate among social scientists regarding the definition and nomenclature of ID. The issue and concept of ID is defined and projected differently by different countries. In some places 'mental retardation' is still preferred while in other places 'learning disability' is used instead of mental retardation. Developmental disability is also used in some countries, for instance, Intellectual Disability is a preferred terminology in United States while learning disability in United Kingdom. Generally, the term 'mental retardation' is considered worthless and socially harmful which should not be used anymore (Smith, 2003). Smith (2003) proposes to abandon any definition of mental retardation and adopting numerous terminologies for developmental disabilities as the phenomena is quite heterogeneous.

Luckasson and Reeve's (2001) criteria for describing ID involves five (5) factors. Firstly, the term should be specific and consistently used by different stakeholder. Secondly, the term must be compatible with current knowledge. Thirdly, the term may easily be incorporated into new knowledge with the advancement in scientific knowledge. Fourthly, the term should also be dynamic in nature so that its operationalization serves multiple purposes such as defining, diagnosing, classifying, and planning supports for disable people. Lastly, it should represent a group of people and based on the value of respect, unlike the term mental retardation which was not communicating dignity or respect which results in the devaluation of such people (Finlay & Lyons, 2005). Hence, there is a substantial consensus on the term *ID* which can meet the criteria suggested by Luckasson and Reeve (2001).

Similarly, there are other reasons as well which support the term ID as compared to MR. For instance, the new construct of disability described by AAIDD and WHO, is

compatible with the existing professional practices that focus on functional behaviors and circumstantial factors (Schalock *et. al.*, 2002, 2007).

Nevertheless, definitional changes reflect the transition from a medical to ecological approach. The ecological definition defines disability in context of individual-environment interaction (Schalock *et. al.*, 2007). WHO's classification (WHO, 2001) also endorses this ecological approach. As opposed to etiology of disability, WHO's classification looks at the impacts of disability in broader social context. As a result, the term ID has been adopted by organizations, journals, agencies and published research by replacing MR. Such developments were accepted and implemented by the President's Committee for People with Intellectual Disabilities (PCPID) in USA, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and the American Association on Intellectual and Developmental Disabilities (AAIDD) (Parmenter, 2004; Schroeder, Gertz & Velazquez, 2002). In Pakistan, however, the term 'mentally retarded' is still used widely in official documents which indicates that Pakistan lags behind significantly from the international standards.

2.7. Type of Intellectual Disability

Besides causes of ID, there are various types of ID which need to be understood. These types of ID are divided into three major types or levels which are determined by calculating the IQ of children. Although these levels or types of disability are replaced by the social or ecological factors like adaptability and behavior of the child in cultural context, however, it is still given weightage for understanding the level of ID according to which various plans of action for education and training are designed.

The first type refers to mild intellectual disability which ranges from ID 50-70 that have minor effects in which a child or person can participate in the social and community activities (IDRS Inc. 2009:3). Furthermore, such children can be educated

up to higher level and can learn, read and write. They can also work, live and travel independently. However, some time they need support and help to handle money and to plan and organize their daily life activities. They have the ability to marry and raise children.

On the other hand, moderate intellectual disability is a condition in which the IDs can enjoy a range of activities with their families, friends, and acquaintances. They can also understand daily schedules or future events provided they are given pictorial/visual aids. Moreover, such persons make choices about work, food and can learn to recognize some words in context such as common signs and symbols such as "Ladies', 'Gents' and 'Exit' mostly given on entrances of buildings. Furthermore, such individuals can look after themselves, however, they need support in the planning and organization of their daily lives activities.

Unlike mild and moderate ID, severe or profound intellectual disability refers to a condition in which a person can recognize familiar people and may have strong relationships with the nearest people surrounding him/her. However, they are extremely poor in speech. Gestures, facial expressions and body language are their only reliable medium of communication. Such individuals require support for their personal care, communication, accessing, and participating in community facilities, services, and activities throughout their life.

2.8. Causes and Types of Intellectual Disability

Research has pointed out a number of socio-medical causes of intellectual disability. Factors which may cause disability in children are explained as follows.

Genetic cause is an established cause of such disability which occurs due to chromosomal disorder (Yannet, 2008) or recessive genetic traits and other blood related complications, most importantly, the unmatched blood group which normally is known

as Rh factor. Besides genetic factors, complication during pregnancy and certain diseases are the root causes of intellectual disabilities. Moreover, intake of alcohol by mother or infection with rubella during pregnancy can also cause ID among children.

In post-natal stage, there are childhood diseases which can cause mortality and ID among children. Other most common causes of ID include cerebral trauma as a result of various accidents in infancy.

2.9. Prevalence of Intellectual Disability

In the preceding section of the chapter, disability and intellectual disability were defined and major causes and types of intellectual disability were discussed. This part of the chapter reviews the prevalent situation of ID in Pakistan with special focus on Khyber Pakhtunkhwa.

2.9.1. Prevalence of Intellectual Disability in World

It is normally believed that Intellectual Disability (ID) can affect people of all group groups, however, children with Intellectual Disability (CID) normally affected more. According to the Report of World Health Organization (1994), there are 156 million people in the world population who inflicted from intellectual disability. However, according to another WHO Report (2011), there are around 785 million people (includes 5 % children) in the world who have either physical or intellectual disability. Intellectual disability is not restricted to developing world only but it prevails in developed countries as well. For instance, six million or 3 % of American Population were detected with mental retardation at some point of their life (WHO, 2011; US President's Task Force, 1960; the President's Panel on Intellectual Disability, 1970).

2.9.2. Intellectual Disability in Pakistan

It is normally believed that Pakistan has a projected population of 180 million (World Population Report, 2015), out of which 45% is constituted of children who are vulnerable to ID. Such prevalence vary from 19.1/1000 for serious ID to 65/1000 for mild ID (Durkin *et. al.,* 1994; Mirza *et. al.,* 2009). However, there is no effective strategy for its prevention in Pakistan. In this regard, researches are required to know its causes and extent of services for the affected children and their parents (Lancet Global Mental Health Group, 2007).

Furthermore, ID in under-developed countries like Pakistan is a public health priority owing to the onset lifetime disability in early age (Jamison *et. al.,* 2006). Such condition also affects the socio-economic development of a country (Institute of Medicine, 2001). The prevalence of ID is much higher in developing countries as compared to developed countries (WHO, 1993). In addition to physiological causes, socio-economic condition is also considered as a major cause of ID. Likewise, underprivileged children frequently experience multiple risks, which increases their vulnerability (Alant & Lloyd, 2005). Poverty and mild intellectual disability are constantly associated (Emerson & Hatton, 2007), since poverty prevents many children from realizing their cognitive potential (Grantham- McGregor *et. al.,* 2007). Intellectual disability occurs when a person experiences "significant limitations in intellectual functioning and adaptive behaviors before 18 years of age" (American Association of Intellectual and Developmental Disabilities [AAIDD], 2010). Between 80 and 90 percent of children with intellectual disability have a mild impairment (AAIDD, 2010).

In developing societies such as Pakistan, ID is concealed due to fear of disgrace (Ahmed, 1995). It is due to lack of proper awareness and education about the causes and effects of ID. Owing to delayed census in the country, the fresh data regarding PWD is

not known, however, there are 3293155 PWD and out of which 8 percent are blind, 7 percent have hearing impairment, 19 percent are physically disable (Census Report of Pakistan, 1998). Out this total, 14 percent are ID and insane [*sic*], 8 percent are suffering from multiple disability.

2.9.3. Intellectual Disability in Khyber Pakhtunkhwa

It is evident from the above literature that the prevalence of ID is much higher in Pakistan, especially in the less developed provinces like Khyber Pakhtunkhwa. According to an official report, "mental backwardness" [*sic*] is the most prevalent type of disability found in the province. In addition, fits, and difficulty in speaking were the other most prevalent complications found in children" (Government of Khyber Pakhtunkhwa, 2011: 12). As result, families got affected negatively due to lack of effective social welfare services.

Furthermore, ID is socially constructed phenomenon. In the rural areas of Pakistan especially in the province of Khyber Pakhtunkhwa, for instance, a teenager with good educational and economic background may be considered intellectually impaired if he/she is unable to entertain family guests (Miles, 1992). Moreover, such children have problems with speech and may exhibit a stubborn behavior. However, it difficult to label someone as ID due to inability to learn and to read in area where less than 30% of adults have learnt to read (Neugebauer, 1987).

Similarly, in most of the South Asian countries especially in Pakistan and India ID is determined either by the family or the community (Naik, 1984:1-2). According to Prabhu (1983), nearly 80% of the people in India were declared as ID on the basis of IQ test but they were declared normal by the family and community due to performance of normal social role as per the expectation of society (also see Miles, 1992).

Furthermore, in the official census of Government of Pakistan (1981), the term "ID was synonymously used as *pagal* ('mad', 'cracked') and *nim pagal* ('half mad')" (US Bureau of Statistics, 1895: 38).

Furthermore, according to an official health survey; ID was named as "mental retardation" and referred to as mental backwardness and poor physical development of a person (Government of Pakistan in 1985). Similarly, the attitude which is a way or approach of a person to define something either positively or negatively also have link with effects of ID in Khyber Pakhtunkhwa. For instance, uneducated families perceived disability among their children as 'Given by Allah or God' and called them 'God's people' or *Allah Wale Log* (in *Urdu* language) and are hesitant to interfere with divine will by treating such people (Badr-a-Haram & Edwin, 1982). Furthermore, it is also believed that the exposure of pregnant woman to the rays of an eclipse or to the shadow of a corpse is considered as one cause of ID. Moreover, parental sins and influence of evil spirits are considered as the other cause based on superstitions (Badr-a-Haram & Edwin, 1982).

On the other side, educated parents in Pakistan are aware of the concept and are more likely to use proper terminology and words (Badr-a-Haram & Edwin, 1982).

2.10. Impact of Child with Intellectual Disability on Family

Family is a functional component of society which varies in structure from nuclear to joint and extended depending on the nature of society. The advent of a new child into the family is an important and generally a happy occasion; however, the arrival of a new member also represents some degree of interruption in the dynamics of the family unit by affecting the relationship between husband and wife. For example, the arrival of additional children naturally represents additional financial and emotional commitments. It also curtails parental recreational and social activities (Chinn, Winn

and Walters 1978). Furthermore, their mobility and travel over extensive distance or time may become difficult because of expenses, inconvenience, and sometimes the uncooperative behavior of the child (Drew & Logan. 1984). The unfortunate birth of a child with some form of disability exerts double socio-economic, psychological, and logistical effect on the family and parents.

The effects of disability on families have always been an area of interest for the social scientists (Philip & Duckworth, 1982). However, researches conducted before 1980s revealed that family dysfunction and pathological reactions were the vital cause of the birth of child with intellectual disability in the families (Byrne & Cunningham, 1985). After the birth of such children, emotional setback and chronic sorrow among the family members was an inevitable and natural response (Olshansky, 1962).

Previous research (see Panek and Smith, 2005) has endorsed that when a child is diagnosed with intellectual disability, it brings upon multiple challenge for the family in term of economic liabilities and social consequences such as negative societal attitudes (Panek, 2005). The agony of the birth of a disable child is sensed in the home by all members (Jamison, 1965). It may also cause emotional disturbances in the parents (Gohel, 2011). Similarly, a child with ID requires extraordinary psychological adjustment on the part of the parents. Moreover, a child with intellectual disability residing with the family, especially a severely impaired child, can increase consumptive demands without increasing the family's productive capabilities. The shock of disable child to the mother may be very serious, causing sometime long range emotional harm (Jamison, 1965). The extreme burdens in the care of the disable child in the home frequently cannot be endured long without some form of external help (Reichman, *et. al.*, 2008).

It has also been found that the mother's health radically affected due to extra involvement with their children. Constant fatigue and nervous exhaustion is common in homes where there is limited help in management of an intellectually disable child. Similarly, most of the parents are reluctant to send their child with intellectual disability to a specialized institution for care, which exerts extra burden of management. However, research has consistently found that mothers of such children report poor mental health who suffer from depression as compared to mothers of normal children (Bailey, Golden, Roberts, & Ford, 2007; Montes & Halterman, 2007).

Apart from direct impact on parents, the birth of such children also has a profound impact on the social functioning of the family as a unit. Such families faces social stigma (Farrugia, 2009). Most families are economically down trodden. Subsequently, their standard of living drops significantly owing to lack of inclusive child-care arrangements (Freedman, Litchfield, & Warfield, 1995; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Shearn & Todd, 2000; Warfield, 2001). Similarly, mothers face challenges in accessing and navigating fragmented, inflexible and/or poorly resourced service systems (McManus *et. al.,* 2011; Murray, 2007; Reichman, Corman, & Noonan, 2008; Rodger & Mandich, 2005).

In traditional societies like Pakistan, the father who is usually the bread-earner may face extra financial burden due to the birth of child with ID as he has to bear expenses of medical, transportational, and educational needs of the child (Boyd, 2011). These children also influence the relationship of non-disable siblings with their parents. As the disable child requires extra care and attention, the siblings usually receive less attention. As a result, jealousy is an automatic response. The siblings long for their parents' special treatment (Cook, 2006).

The impacts of disability are not confined to the family only. Society as a whole has to bear the cost of supporting a large number of disable people who pose a severe drain on economic resources. The existing dependency ration in Pakistan is calculated to be 66% (World Bank, 2015). This does not include population of person with disability. If the estimated 10% of PWDs are included in this dependency ratio, it makes it 75%, adding additional cost to the existing dependency in Pakistan. Public spending on PWDs is minimal in Pakistan. One estimate suggests only Rs. 30/- per year on each person with disability (Shah, 2015).

Many have strongly encouraged the family-centered interventions for IDs (Baker, Landen, and Kashima, 2002). Still, however, there is a lack of research on cross-cultural perspective on family constructs of IDs (Khamis, 2007).

Intellectual disability can affect the child in a number of ways. Briefly, the child is unable to pay attention to day to day activities properly. Furthermore, the child has weak or usually little memory. Resultantly, the child does not develop language ability, gross and fine motor coordination and face problem in learning and problem-solving abilities. Moreover, the child shows poor social and self-care skills and is unable to control his/her emotion and behavior (Department of Health, 2009).

Owing to poor development in the above abilities, the child cannot communicate effectively and is unable to extend self-care. Furthermore, the child is unable to perform household work due to poor social skill. Resultantly, he/she has difficulty in learning and social life in home and community.

2.11. Theories of Disability and Intellectual Disability

Different theories of disability explains 'disability' in different ways. For instance, social causation theory, theory of fundamental causes, social stress theory,

social capital theory, eco-social theory, feminist and gender theory, and queer theory explains the concept and practice of disability.

This section reviews different theories on disability for understanding the concept of disability and prevalent attitude and problems in society in details. It must be noted here that the various theories discussed in the section below explain disability in general, including intellectual disability. Furthermore, it should also be noted that while some of these theories try to explain the causes of disability, such as why disabilities of various forms are found more in one social/racial class than another, other theories explain the social construction of disability and the resultant treatment of disable persons in society.

2.11.1. Theory of Social Causation

The social causation theory assumes that people and groups with low socio-economic conditions are commonly exposed to traumatic life situation, as a result, the chances of intellectual disability are higher among them as compared to groups have sound socio-economic conditions (Aneshensel, 1992). People who have easy access to resources due to sound socio-economic condition are less prone to disability as compared to those who have poor financial condition (Link and Phelan, 1995). Beside, socio-economic conditions, the social and normative structure of society is also responsible for emotional disturbance and intellectual disability.

2.11.2. Social Stress Theory

The social stress theory maintains that continuous exposure of an individual to stress is the cause of intellectual disability. According to Aneshensel (1992), stress is an internally aroused state. It is created by two factors: (1) external demands for normal adaptive ability, and (2) the absence of means to attain a desired end. Cohen and Wills (1985) argues that psychological distress can result from a person's perception that a

situation is threatening and that the individual does not readily have the appropriate ability to cope.

The social structural arrangements within which individuals are nested expose them to differential stressors, consequently, they affect them in a way in which they interpret and experience the stressors (Pearlin, 1989). The availability of resources can enable them to cope with their stressors effectively. Hence, the theory postulates that stress is the cause of mental disability which are normally existed in the social structure of society.

2.11.3. Social Capital Theory

Unlike other theories, social capital theory suggest the coping mechanism for intellectual disability. 'Social capital' in the theory refers to "social networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit" (Coleman, 1988: 94). Social relationship is one of the strength that can overcome the miseries of disability caused by either low socio-economic background or stress. Hence, social capital theory reflects upon the social network and relationship as remedial measure of minimizing the miseries of disability.

This theory states that physical and mental well-being is strongly associated with relationships to others. Community members' interaction can affect health in numerous ways. For example, members transfer norms to each other and new members through interaction. Unhealthy or healthy behavioural norms are also transmitted through interaction. Such norms regarding disability has significant implications for defining disability and PWDs.

The importance of participation of families having children with disability in family gatherings, interaction with friends, neighborhoods, and work is the subject matter of social capital theory. Such bondages may strengthens participation in these

networks and associations. On the other hand, social isolation leads to 'cycle of rejection' (Chenoweth and Stehlik, 2004: 59-72). However, such isolation and rejection can be overcome by building external social capital resources. Social relations refers to the concept of reciprocity, the exchange of resources and supports or services between people. It generally believe that individuals with disabilities and their families have difficulty in interactions with community people due to extra involvement with such children (Chenoweth and Stehlik, 2003).

According to Chenoweth and Stehlik, "it is normally very difficult for a person with mentally illness or disability to challenges the social norm of inclusivity for an individual to overcome the norms of privilege and establish their capacity and place within a community" (Chenoweth and Stehlik, 2004: 63). Owing to disability, people are kept away from the mainstream society. However, if they have access and command over resources, then, they will be able to make decision in their interest.

2.11.4. Economic / Marxist Perspective of Disability

The economic perspective explains the public disability benefits and economic productiveness of individuals with disability in society and also reflects upon the economic implication of sidelining the huge population of persons with disability. According to WHO (2011), among one billion disable people in the world, mostly contain of women, older people, children, and adults who are poor as well (WHO, 2013). They faces discrimination and which not only arises human right issues but has strong economic implications as well. Hence, it is estimates that the economic losses incurred through excluding persons with disabilities from the world of work are as high as 3-7% of global GDP (World Bank, 2010).

Furthermore, disability is often defined in economic perspective as 'condition that affects an individual's ability to work for wages'. According to Charlton (2006)

> People with disability have been socially oppressed which made them less economically productive members of society and view them as part of the ''underclass'' due to their lack of participation in wage labor (Charlton, 2006: 218).

According to Marxist Sociologists, capitalist system exploits social position, health and disability for controlling over the societal resources and means of productions (Lynch and Kaplin, 2000). On the other hand, the non-capitalists normally either have fewer or lack resources, consequently, they are prone to exploitation in society.

According to Marxists, industrial capitalists marginalized people with disability due to their "disability" as they requires persons to sell their labor to the owners of the means of production. However, persons with disability are normally unable to sell their labor on the same terms as non-disable individuals, subsequently, they are being excluded from the industrial production system (Gleeson, 1997; Oliver, 1999).

On the other hand, postmodernist and poststructuralist theorists such as Corker, (1999) criticize Marxist by arguing "that disability is more properly viewed as constructed "within linguistic, discursive, and cultural practices" (Thomas, 2002: 23), "rather than based in a fixed or objectively true characteristic or status of a disable person" (Thomas, 2002: 24).

2.11.5. Gender and Feminist Theories of Disability

Gender and Feminist theories of disability normally highlights males' dominance and women oppression in society. They also focus on ways that disability challenges predominant and stereotypical notions of gender performance (Cheng, 2009) as disability is normally viewed as a feminine characteristic (Thomson, 2002) while independence, ability and strengths are views as male characteristics (Ferri & Gregg, 1998).

Similarly, feminists also surface the miseries of caregivers who are generally women across cultures by endorsing that mothers as caregivers generally occupied an

unrecognized status both in the disable people's movement and disability studies (see, Voysey, 1975; Birenbaum, 1992; Veck, 2002). Feminists argues that women due to caregiving roles are in relationships with disable dependents such as children with intellectual disability as very few men than women consider caregiving as a self-affirming role (Cohen, 1996). Hence, women contribute a lot to society as caregiving, however, such role has never been recognized and appreciated by their male member of society.

2.11.6. The Social Construction Theories of Intellectual Disability

The social construction theory of disability is based on the sociological theory of 'Social Construction of Reality' which was introduced by Berger (1966) and Luckmann (1966). The basic argument of this theory is that reality is socially constructed and sociologists must understand it within a social context. In the other words, it talks about the social relativity which states that the concept of 'reality' varies from society to society (Berger and Luckmann, 1966). Hence, the theory was conceptualized as the social construction theory of disability which group in power set guidelines for describing normality and abnormality (Dewsbury *et. al.*, 2004; Turner *et. al.*, 1996; Tregaskis, 2002). Resultantly, disability is considered as a social deviance (Dewsbury *et. al.*, 2004 and Turner *et. al.*, 1996). This theory defines that disability is neither a social deviance nor a disease; rather it results from environmental and social structures that causes social exclusion of individuals with disability from social sphere.

This theory has not only surfaced the problem of disability but also mobilized a movement for the rights of disable as a reaction to the oppression of a person with disability by the groups in power who define normality and disability. Thereafter, this struggle laid the foundation of the social model of disability (Mays, 2006; Oliver; Rothman, 2003; Tregaskis, 2002). This model is the frame of work which says that

disable are oppressed in society due to unusual appearance and sexuality (Anderson and Kitchin, 2000). Owing to such oppressive attitude of society, they are not considered eligible parenting. Furthermore, due to unfavorable structure of society, there is institutional discrimination against them, due to which these people are unable to seek jobs and live an economically empowered life.

There are three aspects of social constructionism related with intellectual disability and special education (Nunkoosing, 2000). First, anti-essentialism rejects the claim that there is only one cause of intellectual disabilities, hence, ID requires multiple perspectives and possibilities for understanding it as reality. Similarly, anti-realism "theorizes that there is not only one objective, observable and measurable reality that is external to the individual" (Nunkoosing, 2000: 52). Rather people actively engaged in yielding new knowledge based on their experiences and interactions with the world around them.

The identity of ID is not related to mental processes but always determine how one interact and behave with people in social life (Marling, 2004; Goodley, 2001). Furthermore, people with learning disability are intentionally placed in special education centre just to exclude them from mainstream society which will service the interest of vested-interested group (Tomlinson, 1982). Thus, the political, historical, social and economic context need to be understood while dealing the rights of persons with disabilities (Carrier, 1986a).

Summary

To summarize, various theoretical perspectives of disability were discussed in the above section. Each theory focuses on a specific dimension of disability. The social causation theory maintains that low social condition and deprivation are the root causes of all types of disability in society. The social stress theory also reflects the same

deprivation-caused stress and disability in society. The social capital theory focuses on the social relationship and social network by the people with disability which is believed to be helpful in minimizing the adversities of disability. The eco-social theory talks about disability and environmental factors that cause disabilities. The Marxist economy theory of disability argues that the common people possess fewer resources, have less control over resources and are vulnerable to exploitation, exclusion, and domination by the capitalist class. Feminists have highlighted the exploitation faced by women due to womanhood and disability. Feminists react to societal attitude that disability is a feminine characteristic.

In addition to these theories, the social construction theory of disability also discussed the idea that dominant groups set guidelines for describing normality and abnormality (Dewsbury *et. al.*, 2004); Turner *et. al.*, 1996; Tregaskis, 2002). Resultantly, disability is considered as a social deviance (Dewsbury *et. al.*, 2004; Turner *et. al.*, 1996). This theory defines disability as neither a social deviance nor a disease rather it results from environmental and social structures that cause social exclusion of individuals with disability from social sphere.

2.12. Effects of Child with ID on Families and Fundamental Confusion Regarding the Concept of ID

It is normally believed that one percent of the world's population suffers from intellectual disabilities, which mostly found in developing countries (Maulik, *et. al.*, 2011). However, the issue of ID has not been taken with equal seriousness across the world (Villamanta Disability Rights Legal Services, 2012: 7) due to lack of consensus on a comprehensive title, definition, criteria for determining ID and cause of ID (Michaelson, 1993: 34). Therefore, children with intellectual disability are considered as

"minority within a minority" (Munn, 1997: 484-486.), hence, such indifference causes problems for the families.

2.12.1. Lack of consensus on terminology

Lack of consensus on single terminology is considered as the first reason which make ID among children as the least interested problems. ID is widely termed as 'Mental Retardation' (MR) in old as well as new literature. However, ID is mostly considered as the preferred terminology but still there is no consensus on the term ID in different countries. Consequently, different concepts are used such as mental retardation, intellectual disability, developmental disability, learning disability, and cognitive disability etc. The phrase "Person with Mental Retardation" is widely used in Pakistan, but it is considered as offensive terminology in United Kingdom, where Learning Disability is used while the same terminology is also used in Australia (Fernald, 1995). Fernald (1995) suggests that the term 'Intellectual Disability' is neutral and less harmful terminology, consequently, the international community is adopting intellectuali Disability instead of mental retardation (Schalock, *et. al.*, 2002).

Hence, owing to lack of consensus on a single terminology, such issues have always been interpreted into local jargons in Pakistan such as madness and aloofness which cause stigma for the families.

2.12.2. Lack of consensus on definition of ID

Similarly, lack of consensus on a single definition of ID has made the issue ambiguous and complicated. The consistent changes in the definition was criticized by John Jacobson, former president of the AAMR Psychology Division, that "The new AAMR manual is a political manifesto, not a clinical document" (Michaelson, 1993: 34). The frequently changes in terminology is a political tactics just to keep the issue intellectual disability ambiguous and less important. Furthermore, according to

Hourcade, "the names and terminologies changes with the passage of time, however, such changes must not distract professional and families from their actual goals, i.e., to provide high level of support to persons with ID in schools, work and residential environment" (Hourcade *et. al.*, (2002:6-8).

In short, the title, definitional and other controversies are the tactics used for misguiding society, families and parents which cause negative consequences for them.

2.12.3. Lack of consensus on the type of ID

Just like the problem with the title and definition, the criteria for determining the level or type of ID have also been confused. Controversies are associated with the assessment of intellectual functioning centuries. Alfred Binet developed a well-known testing tool known as IQ tests. These tests assess the person's general knowledge, vocabulary, problem-solving skills, and reasoning ability. There was standard score that need to be achieved, for instance before 1973, the recommended IQ standard score for ID was 85 which was revised thereafter by 70 was kept as cut-off score for ID. However, it was revisited and the low IQ score was not insufficient for a diagnosis of ID as low IQ must be considered along with limitations in adaptive behavior. In such condition, adaptive behavior was referred to those social and practical skills that required for effective functioning in their everyday lives such as communication, social interactions, taking care of oneself, managing money, and using transportation, among others. However, still this levels of support system has not been accepted as widely as the traditional system based on IQ scores (Conyers, Martin, Martin, & Yu, 2002).

In 1992, the AAMR listed more than "350 conditions" in which can cause ID (Lukasson *et. al.*, 1992), however, today these causes exceeded "750 conditions that can cause ID" (Diagnostic Statistical Manual of Mental Retardation (DSM-MR)-5:104). Owing to these ambiguities, it generally believed that 70 % of the causes of ID are not

known (Jaffe, 2000). While, the known causes are chromosomal abnormalities, metabolic disorders, embryonic teratogen exposure, complications during delivery, and childhood illness or injury (Jaffe, 2000).

In short, owing to lack of authentic and uniform system of diagnosis about the types and causes, such disability is normally dealt with improper methods of treatment normally employed for mental disorders. Such confusion have restricted such disability to families only, consequently, it affect families negatively.

2.12.4. Effects of ID on families

As far the adverse effects on families due to negative attitude towards child with ID are concerned, they vary from family to family and society to society as it challenges family roles and patterns of family organization (McDaniel and Pisani, 2012). ID differs from many others in that they are "invisible," hidden in the brain and intra-psychic experience of the affected individual (see McDaniel and Campbell, 1999). Most of the causes of many ID, as explained above, are unknown and the ways in which they impair can be subtle and unpredictable. Thus, families coping with ID face the dual stress of social stigma and ambiguous loss (Ibid).

Walsh (2003) has identified three areas of family functioning which are organization patterns, family belief systems and communication processes (Walsh, 2003). Family organization patterns refers to systems which have distinct structures such as roles, boundaries, hierarchy, and connectedness yield patterns of interaction, expectation, and support (McDaniel *et. al.,* 1992). Hence, nuclear families are vulnerable to dysfunctions than joint families in Pakistan due to limited role, family members, support and connectedness. Moreover, negative attitude towards child with ID affect and is affected by the believe system of family which refers to a distinct identities and world views that shape how they adapt to stress and change (Rolland, 1994). Another

is such belief system also play a vital role in dealing with intellectually disable children in family.

As far communication functioning of family is concerned, it is reflected in clarity, open emotional expression, and collaborative problem solving as the key elements of healthy communication which connects and empowers stressed families (Rolland & Walsh, 2006). Similarly, family members often requires frequent information exchange, decision-making, and cooperation for sharing care (Walsh, 2003). Hence, social support and communication in joint family system for parents having such children is higher, consequently, they face less stress (see Sajjad, 2007, 2011) due to good social support from close family members and friends than for individuals with inadequate social support (Lahey, 2002: 367).

Therefore, effects on families is not similar in developed and under-developing societies due to variation in socio-economic and culture realities. The euro-centric literature discussed effects of child with ID ignore social diversity of societies, consequently, the adverse effects has not been understood properly.

2.12.5. Patriarchy and effects of ID on families

In most societies of the world, particularly in developing countries, it is normally believed "that household is the domain of women while public and politics are the domain of men" (Jalal-ud-Din and Khan, 2008: 485). Within such normative parameters, male in Pakistan is primarily consider as breadwinner, while female is taken as care taker of family (Malik and Khalid, 2008). Among parent, mother faces lot of stress as compared to father due to close association with her child at home. She has to extend care to such children along with all household work and taking care of other non-handicapped children (Sajjad, n.d).

Owing to patriarchal structure of society, women are solely responsible for household management and primary care while men are responsible for earning, decision making and other matter mostly practice outside the family. Men as husband if wish to help her in such care-giving is normally taunted in society and considered him as weak and henpecked. So, helping wife is culturally considered as shameful activity. Resultantly, the care-giving burden of children with ID is considered as the primary responsibility of mother only while father remains mostly exempted from such burden. Hence, owing to patriarchy, mothers of child with ID are effected more as compare to fathers.

2.12.6. Effects on families due to stigma associated with ID

Similarly, family generally perceive ID according to their distinct belief system. However, such belief system is based on lack of information and knowledge about the cause, type and copying of such disability which leads them to superstitious beliefs, behaviors and practices which affects family resources and child's development and recovery badly. In Southeast Asia, ID is considered as stigmatized and shameful condition as it is associated with punishment for the sins that one's ancestors have committed (Hampton & Xiao, 2007). The occurrence of ID brings shame and feelings of inferiority for the families which mostly reduces the amount of social contact that the family has with others in the community (Ali, 1997; Ali, *et. Al., 1994*). Even non-disable children abstain from playing with children having ID. In short, the parents and family members faces guilt, embarrassment and feelings of failure (Ali, 1997: 9).

2.12.7. Perceived Effects of ID on working mothers

Similarly, the effects of poor attitude towards child with ID is also not similar on all mothers as reflected in literature mostly produced by developed societies. Working mothers are affected more as compared to non-working mothers by the presence of

face difficulties to integrate their work roles and responsibilities and manage time with household chores (Grady and McCarthy, 2008). Based on the stress-strain model of Dunham (1984) and social identity theory of Lobel (1991), Ahmad (2008) has developed a predictive model for family-work conflict. She has categorized work, family and personal factors that creates imbalance in family-work for working women. These factors includes; work time commitment, job type, job involvement, life-cycle stage, number of children, child care arrangements (family-related factors) and role values, gender role orientation, locus of control, perfectionism as individual-related factors (personal-related factors). Hence, in patriarchal societies, the role of women both at home and work is normally not appreciated and acknowledged (Fernandez Kelley, 1981).

Consequently, mother as primary care giver has to bear the burden of care-giving, household management and work. Such role conflict exert psycho-social pressure such as anger and sense of loneliness and depression that afflict them with psychological and physical ailment (see Miles, 1987).

Summary

The term disability is considered as stigmatizing term which may hurt the person with special needs. Similarly, the use of terminology of mental retardation is equally offensive and stigmatizing, hence, different countries adopted different terminologies by keeping in view their own social structure. For instance, in Pakistan, the term mental retardation is still used in their day to day jargon and official documents, while in the United Kingdom, learning disability is used instead of mental retardation. Similarly, developmental disability is used in Japan and Australia while in United States of America, the term Intellectual Disability have been adopted recently.

As far the causes of intellectual disability is concerned, it is not limited to one cause, there are multiple other causes which are still unknown and the medical science fail to find out the cause of intellectual disability among children. Similarly, intellectual disability is categorized into three major categories, which are even debatable among the social scientists.

Social causation theorists focus on how low-social status groups show higher rates of mental disorders. The social stress theorists, on the other hand, maintain that continuous exposure of an individual to stress have a strong link to disability. The economic perspective looks at disability in terms of economic losses caused to society by disability. The feminist theorist stress upon the female disable population. Social construction theorist assert that the dominant groups in society set guidelines for describing normality and abnormality.

CHAPTER 03 SOCIAL WELFARE AND SPECIAL EDUCATION IN PAKISTAN

This chapter explains the concept of Social Welfare in chronological order starting from conceptual background to historical background of social welfare and finally discusses the current administrative structures at both federal and provincial level of Pakistan. To elaborate in detail, the concepts of Social Work and Social Welfare are explained first as these are normally confused and used synonymously. An effort is made to differentiate these concepts for the readers. For this purpose, this chapter is divided into four parts. Part 1 explains the conceptual and theoretical dimension of social welfare and social work. Part 2 explains the concept and practice of social welfare in Pakistan in historical perspective. An effort is made to explore the causes of poor Welfarization in the country. Part 3 explains the social welfare structure and setup at federal level of Pakistan which consists of organizational structure, budgets and types of services while the last part explains the structure of social welfare at the provincial level in Khyber Pakhtunkhwa.

The purpose of these deliberations is to find the gaps in theory and practice of social welfare in the country in general and in Khyber Pakhtunkhwa in particular and the impact of these gaps on the services for children with ID and on their families in mitigating their problems causes such indifferent attitude of society.

Part I

3.1. The Concept of Social Welfare

Social welfare is generally about helping people facing contingencies (Sajid, 2008). The modern term used for social welfare is social protection nets in a society at a

given time (Sajid, 2008). Social welfare refers to various social actions that are required by individuals and groups to tackle social problems in society (Alcock. *et. al.*, 2014).

There are three sources of social welfare in society that existed in all most all societies with slight variation. These sources are family and friends, the state, and non-governmental organizations (NGOs) such as voluntary organizations, mutual associations, and charities (Alcock. *et. al.*, 2014). Generally social welfare covers all aspects of life starting from birth to death and provide social services when other institutions failed or are inadequate (Day, 1997). Social services are normally extended for eradication of hunger, delinquency, or substance abuse in society.

The exact nature and definition of the concept of social welfare varies from society to society depending upon their economic condition. Likewise, there is no universal definition of the term social welfare as societies have different structures and have different means of fulfilling their needs. For example, in the first world countries, welfare refers to the entire range of social services including education, health services, public ways and roads, policing etc. while in the developing countries it has a different scope. In Asia-Pacific region, which includes Pakistan, the term is either used to describe those services which are required by the vulnerable sections of the society and includes services for the handicapped and the traditionally under-privileged groups such as the poor classes and women (Gore and Khandekar, 1975).

3.2. Social Work and Social Welfare

The terms social work and social welfare have some basic differences. Social welfare refers to system of social services that covers social work, public welfare and other related programs and activities. While social work is a profession that enable people to solve their problems effectively by strengthen their social relationships (Skidmore, *et. al.*, 1994).

Social welfare, as referred to above, covers all aspects of one's life in a society, however, in some societies it is limited to needy people only. Broadly speaking, there is no society in the world where there is no social problem (Dubois & Miley, 1996). The problems of poverty, ill health, age related problems, child abuse, violence in the families, substance abuse, discrimination and prejudice, unequal access to resources and unequal distribution of resources, education problems etc. do exist in most cases if not in all societies that need a solution (Sajjid, 2008).

As discussed above, there is a difference in social work functions in different societies. This has been explained and elaborated further in the following section.

3.4. Perspectives on Social Welfare

A perspective is a viewpoint based on values from which to look at a phenomenon. Our perspectives on social welfare come from diverse values that determine what we think social welfare should do and what its causes, purposes, functions and results ought to be. Traditionally, social welfare is considered as philanthropy that aim to help needy. However, professionally it is system of welfare that aim to develop the structures and institutions of society for the welfare of society. (Day, 1997).

There are four perspectives or philosophies in social welfare that explain the function and extent of social welfare in society.

- Residual perspective
- Institutional perspective
- Developmental Perspective
- Conflict perspectives in social welfare

3.4.1. Residual Perspective

Residual literally means left-over or remaining. The residual perspective regards "social welfare as service required in problems and gaps, based on the belief that it will benefits people only when they fail to provide adequately for themselves" (Andersen, 1996: 265). According to this perspective, it is the people's own fault if they require outside help, hence, in such helpless situation, society should assist them till they meet their own needs. This model associate helpless with women and children who always need welfare services. This reflects capitalist view. This perspective is similar to medical model of social work in which services are only for the treatment of people who are always dependent. This complex of ideas leads to blaming the victim (Ryan, 1971) as responsible for her or his own problems and does not consider structural problems such as lack of employment opportunities or special problems as relevant.

3.4.2. The Institutional Perspective

Institutional perspective is the opposite of the residual perspective. According to this perspective, "every person has a right to services, without stigma" (Blau and Ambramovitz, 2010: 153). Unfortunate situation can any time affect people, hence, in such situation people have a right to receive benefits and services on an ongoing basis. Similarly, "Society has a responsibility to support its members and provide needed benefits and services" (Blau and Ambramovitz, 2010: 153). Institutional perspective is a more humanitarian and supportive approach than residual in helping people. Provision of education for enhancing people status is the core aim of this perspective (Dittrich, 1994).

3.4.3. The Developmental Perspective

Unlike residual and institutional perspectives, developmental perspective looks into social interventions that have a positive impact on economic development (Midgley

& Livermore, 1977). This perspective emerged after World War II for the purpose of designing social welfare programs that would enhance economic development in less developed countries. This perspective gained motivation in the US in 1970s because "it justifies social programs in terms of economic efficiency criteria" (Lowe, 1995; Midly & Livermore, 1997: 575).

Midgley and Livermore (1997) have identified three major ways in which economic development can occur in a development context. First, "investment in services to people such as education, nutrition, and health care can be evaluated so that people get the most for their money" (Midgley and Livermore, 1997: 577). For example, investments in education may result in a more skilled labor force and, in turn, generate a stronger economy. Second, investment in physical facilities involving "the creation of economic and social infrastructure, such as roads, bridges, irrigation and drinking water systems, clinics etc. which work as the economic and social bases on which development efforts depend" (Midgley and Livermore, 1997: 577-578).

Third, "developing programs that help needy people engage in productive employment and self-employment are more economically viable than giving people public assistance payment over years and even decades" (Midgley and Livermore, 1997: 578). In short, an efficient economic investment needs to educate and train people in getting jobs and eventually support themselves to live dignified life.

3.4.4. Conflict Perspective in Social Welfare

Conflict perspective is based on conflict theory. It posit a conflict between those who control society's structures and those who are controlled and exploited by them. Piven and Cloward (1996) were among the first to develop these theories, noting that throughout history, whenever the disadvantaged rebelled against exploitation, welfare programs and benefits were expanded until the rebellion ceased. Then, although benefits

shrank, it was seldom to pre-rebellion levels and they were sufficient to keep people quiet for a time. Thus, expansion of welfare programs was not altruistic but political and economic: it quelled rebellions and, because benefits were always meager, it kept a quiescent work force eager to take jobs with low wages and few benefits. This made labor costs cheap and profitable to producers.

Socialist feminism's primary concern is "the economic oppression of women, which began with the onset of private property and the loss of women's economic value to the family" (Denmark, 2016 *et. al.*:16). In this view, women are particularly oppressed; first as workers in capitalist economy and second as wives dependent on husband who exploited them by benefiting from the work they do at home as well in market. They involved in un-recognized work with their four-wall and at the same time produce children who are cheap labour for them. Radical Feminism is concerned with "political exploitation of women under a patriarchal system enforcing gender privilege throughout history" (Kimmel and Aronson 2004:299). In this view, both class and gender exploitation began with the onset of private property and the loss of women's co-equal status. Patriarchy sex-role socialization keeps women in subordinate and powerless roles and increases their dependency on men and male systems (such as public assistance and mental health systems), so that women themselves believe in the "rightness" of male control and cooperate in their own subordination. Models for action include consciousness raising; values awareness; a reassessment of female roles in marriage, family and society; and social action for empowerment even to the point of separatism, as in women's communities.

3.4.5. The Liberal-Conservative Continuum

According to conservative-liberal continuum, the purpose of welfare program are how people should be served by social welfare programs (Dolgoff, Feldstein, & Skolnik, 1997).

3.4.5.1. Conservatism

Unlike institutional and development perspective of social welfare, conservatism refers to a philosophy reflects that individuals are responsible for themselves, hence, government should help them at minimum level (Popple and Leighninger, 1999). This perspective oppose change and flourish on tradition by keeping things as they are. Moreover, this perspective mostly have "pessimistic view of human nature as being corrupt, self-centered, lazy, and incapable of true charity" (Popple and Leighninger, 1999: 7). Furthermore, conservatives usually perceive that people are capable of taking care of themselves if they work hard, they can change their life in better way. In short, people on welfare do not deserve such resources, rather they should be taking care of themselves (Karger and Stoesz, 1998).

3.4.5.2. Liberalism

Liberals are against status-quo and prefer changes by thinking that there is always a better way to get things done (Popple and Leighninger, 1999: 6). Moreover, "liberals are optimistic about human nature by believing that people are born with infinite possibilities for being shaped for the good, and, if not corrupted are naturally social, curious, and loving" (Popple and Leighninger, 1999: 7). Furthermore, liberals believe that "people are significantly affected by things in their environment, their free will is limited by environmental obstacles such as racism, poverty, and sexism, among others" (Karger & Stoesz, 1998: 8).

3.4.5.2. Radicalism

According to this perspective, welfare to people can be ensured by drastic and fundamental changes in social and political structure to achieve true, fair, and equal treatment. For instance, poverty is the result of exploitation by the ruling or dominant class. They keep them on low wages, however, when low paid workers complain, they simply fired them as result they hire some else who eagerly waiting to take their place in order to avoid poverty. Thus, working class serves the wealthy due to their poverty. While capitalists keep them in poverty just to maintain their prestige and status in society.

Hence, in such situation, welfare of people can be ensured by deconstructing the already existed dysfunctional institutions and social structure.

Summary

Social welfare is about helping people facing contingencies. Social work is a part of social welfare which is an academic discipline and a professional way to help people in solving and preventing problems in social functioning, strengthen their social relationships, and enrich their ways of living. It is both a field and a method. To understand the system of social welfare more critically, various theories explain the concept of social welfare. Residual perspective social welfare provides benefits and services to people who fail to provide adequately for themselves, hence, society helps them by providing social welfare series to them. The institutional perspective says that every person has the right to social welfare services without discrimination while developmental perspective seeks to design social welfare programs that would also enhance their economic development. On the other hand, conflict perspective of social welfare argues that it is the conflict between those who control society's structures/resources and those who are controlled and exploited.

Part II

3.5. Emergence of Social Welfare in Pakistan: Historical Perspective

This part focuses on the development of social welfare in Pakistan. These developments are critically discussed in historical perspective for exploring and understanding the root cause of poor welfarization in the country.

Social Welfare in Pakistan had always the lowest of the low priority in social sector programs and suffered the most when, due to heavy debt burden, and dwindling foreign loans from the IMF and the World Bank, the resources became scarce. This inherent weakness in social welfare can be seen right from the inception of Pakistan. After creation of Pakistan 1947, there was need of an indigenous system of social welfare for healing the newly migrated people from India. Pakistan was created with the slogan of Islamic ideology which was supposed to provide relief to people through the philosophy of Islamic welfare. These philosophies were also reinforced by the Leader of the Nation, Quaid e Azam Muhammad Ali on different occasions. For instance, he once said:

> "The Western economic theory and practice will not help us in achieving our goal of creating a happy and contented people. We must work our destiny in our own way and present to the world an economic system based on true Islamic concept of equality of manhood and social justice" (Khilji, 2005: 366).

On the occasion of All-India Muslim League gathering at Allahabad in 1942, he was asked about the structure and function of Pakistan. He replied:

> "…Pakistan will be an Islamic State based on the model of Medina State with the philosophy of human rights, liberalism, democracy and complete tolerance and freedom of conscience"…(Ahmad, 2001: 1137).

However, after the demise of the leader, his guideline was sidelined and the state machinery went for begging the United Nations for assistance. Hence, the UN have devised a 'Social Welfare Model' based on the western philosophy in 1951. Thereafter,

the downfall of the social welfare sector in the country started. This help made the people of Pakistan dependent of foreign donations which was completely against the vision of Jinnah. Consequently, system of social welfare has never been succeeded since 1951 in overcoming social problems of the country due to incompatible philosophy of capitalism. As a result, Social Welfare consistently remained stagnant sector in Pakistan which is running on foreign donations.

3.5. Emergence of Social Welfare (Social Work): Historical Perspective

In 1951, the Government of Pakistan sought the assistance of the United Nations with a view to formulate a social welfare program helping her to overcome the problem of settlement. Hence, UN experts arrived Karachi which was the beginning of a new orientation in the field of social welfare.

In the absence of trained social workers, the UN experts advised the government to give priority to social work training because without qualified workers, social welfare projects and programs cannot be properly implemented. On the recommendations of the UN Adviser, the Government of Pakistan (Health Division) drew up a plan for initiating an organized social welfare program in the country in 1953.

Table 1: Emergence of Social Welfare and Social Work in Pakistan

Training and Education of Social Work	Social Welfare Institutional Mechanism
1st short term in-service training was started on Oct. 2,1952 & completed on April 2, 1953 in Karachi	Planning Board was established in 1953
2nd short term in-service training in Dhaka (East Pakistan) started in July 1953	Ministry of Social Welfare and Local Self was established in 1954
3rd short term training was started in February1954 and ended in July 1954 Karachi	National Counsel of Social Welfare (NCSW) was established on July 2, 1956
Two Year diploma in Social Work was started by Punjab University on Nov 13, 1954	Provincial Counsel of Social Welfare was established in all provinces in 1957
M.A Social Work program was started by the University of Dhaka in 1958	
M.A Social Work program was started by Punjab University in 1956	Central Directorate of Social Welfare was established in Karachi in 1958

M.A Social Work classes started at the University of Karachi in 1962	Directorates of Social Welfare was established in 1964
M.A classes started at the University of Sindh in 1967	Provincial Directorates of Social welfare were established in 1970
M.A classes started at the University of Baluchistan in 1974	Allocation of funds for Social Welfare started from the 1st Five Year Plans 1955-60
M.A classes started at the University of Peshawar in 1976	Social Welfare Policies: 4 Social Welfare Policies existed since then,1955,1988,1992&1994

Source: Rehmatullah, S. (2002). Social Welfare in Pakistan. Karachi: Oxford

In the initial stage, the government's responsibilities were confined to imparting social work training, encouraging voluntary agencies and sponsoring of urban and rural community development projects. With the assistance of the UN, the country had taken the certain steps in developing Social Welfare System in Pakistan.

3.7. Welfare Departments and Other Relevant Bodies

The government of Pakistan intended to establish a mechanism for overcoming the miseries of newly migrating people from India to find solutions to various social problems, hence, Planning Board was established in 1953 to formulate a strategy of economic development for the state. A social welfare section was created in the Planning Board to explore social evils and social needs arising out of social change and economic development in the country; to review the social policies and legislation in the various fields of social welfare; and to prepare a five-year plan for social welfare programs.

Thereafter, National Council of Social Welfare (NCSW) was established in 1956 to expedite welfare activities of voluntary organizations by providing them financial assistance and consultative services. Afterwards, provincial councils were made in the provinces with the objective of helping the voluntary welfare agencies.

The central Directorate of Social Welfare was abolished in 1962 and the Directorate General of Social Welfare was created in the government of the then West Pakistan (now Bangladesh) in September, 1964.

After the division of 'One Unit'/West Pakistan in July, 1970, the former provinces of Sindh, Punjab, Khyber Pakhtunkhwa (previously known as North West Frontier Province) and Baluchistan were revived. As a result the West Pakistan Directorate General of Social Welfare and the West Pakistan Council of Social Welfare were bifurcated into four parts. One Directorate and one Council were established in each province as such. In other words, two principal organizations were set up by the provincial governments to look after social welfare programs in their respective provinces. In 1979 a separate department of Social Welfare was established. Afterwards in 1996, the segment of Women Development and in 1998 the segment of *Bait-ul-Maal*[1] were also attached with Social Welfare Department. Later on in 2012, a separate department of Women Development was established and the segment of women development was separated from Social Welfare and *Bait-ul-Maal* Department.

The social welfare policies and strategies that were framed during this period were based on the vision and philosophy of the rulers of the country and were meant to satisfy their political goals rather than deal with the social problems of the people (Rehmatullah, 2002:51-52). The very concept of social welfare, developing people's capacities to help themselves their own problems through community development and people's participation, and the idea of self-reliance were misconceived and given low priority (Ibid.)

Though, the UN experts had considered *Zakat* (Islamic charity) system as the most innovative for of public assistance, and had recommended that this vast resource be mobilized for social welfare (Ibid:227) in initial stage. However, nothing has been done in streamlining this system for public welfare. After 30 years, it was realized by the then President General Zia Ul Haq in 1980 who formulated *Zakat and Ushr Ordinance* 1980.

[1] *Bait-ul-Maal* is Arabic word meaning "house of money" or more generally, "Public Treasury" which is an institution of working for the social welfare of destitute in the country.

Under this law and system, many destitute people are supported, however, if the *Zakat* system is properly administered, it can become a huge safety net for the poor and the indigent. Though, there is strong criticism against small handouts given to the widows and the needy which only seems to create dependency, hence, the system needs to be reviewed so that people can become more self-reliant, rather than dependent on small doles (Ibid: 229).

The second cause of the failure of social welfare in Pakistan is the adoption of imported ideas of social welfare in the form of literature, curriculum and training at academic institutions. The UN had recommended training and education of social work as the only solution for running the social welfare system. However, instead of developing our own curriculum and courses, the country started adopting the imported ideas of the western philosophy of social work and social welfare. As result, such trainings helped the graduates in getting their degrees and jobs but failed to seed solution for the social problems and provide relief to poor segments of the society.

This failure is evident from the rapid development of social welfare ministry, administration and education, which are developments only on paper; in reality the poor is getting poorer.

Summary

This part explains that social welfare has always been a low priority of the state in Pakistan since its inception. Pakistan could have a model social welfare system in the world if it could establish the system of social welfare based on and embedded in the social welfare philosophy of Islam and according to the local cultural values. Various administrative structures have been established and abolished over the years. The National Planning Commission was established in 1953; the National Council of Social Welfare was established in 1956; the Central Directorate of Social Welfare was

abolished in 1962 and in 1979 a separate department of Social Welfare was established. Afterwards, in 1996, the segment of Women Development and, in 1998, the segment of *Bait-ul-Maal* was attached with Social Welfare Department. Later on, in 2012, a separate department of Women Development was established and the segment of women development was separated from Social Welfare and *Bait-ul-Maal* Department.

Part. III

3.8. Social Welfare in Pakistan at Present

In order to understand the administrative setups of social welfare, the Directorates of Social Welfare, Special Education at Provincial level, Directorate of Social Welfare, and Special Education at federal level are discussed in detail in this section.

As far the present setups of Social Welfare and Special Education in Pakistan are concerned, these are operational both at federal and provincial level. There is a Federal Directorate of Social Welfare and Special Education which is run and financed by The Federal Ministry of Social Welfare while the other setup of social welfare is known as Provincial Directorates of Social Welfare and Special Education which is governed and financed by the Provincial Ministry of Social Welfare.

In the following section, Federal Directorate General of Special Education is discussed first.

3.9. Federal Directorate General of Special Education (DGSE), Islamabad, Pakistan

The needs and problems of person with disability in Pakistan was brought into focus in 1982 with the observance of 1981 as the United Nations International Year of

Disable Persons (Govt. of Pakistan, 2016). As result, National Special Education Centres were established at Islamabad in 1982 (see Table 2).

The Directorate General of Special Education (DGSE) was established in 1985 under the Ministry of Health, Social Welfare & Special Education through Presidential Directive 1980 with the aim to provide enabling environment and opportunities through policies, plans, programs, and projects that would promote social progress, educate, and rehabilitate children / persons with disabilities and vulnerable groups of the society.

This Directorate is responsible for preparation and execution of policies and plans for education and training of person with disabilities. The Directorate has a managerial and operational team consisting of the following members given in the form of organogram (see annexure 2, 3, & 4 of this thesis).

3.10. Special Education in Pakistan

In this section, Special Education in Pakistan is discussed to highlight the type of services provided for the rehabilitation of children with special needs.

As far as education of children with disabilities is concerned, it is normally believed that the effort of educating children with special needs was started long ago. The Government of Pakistan identified its responsibility for training and educating these children for the first time in the report of Commission on National Education, 1959 (Ahmad &Yousef, 2011). However, the proposal to provide education for these children was not made until the Education Policy 1972-1980, and in the Fifth Five Year Plan (Rehmatullah, 2002). Thereafter, a handsome amount was allocated for special education. Later on, in 1980s, a much greater government interest was found, which resulted in increased budgetary provision for special education. Similarly, during 6th Five Year Plan (1983-1988), social welfare program aimed to strengthen social welfare

and special education. As a result, the Federal Directorate General of Special Education with provincial counterparts was set up in 1985 for catering to the organizational needs of the special education sector.

Currently, a number of special education institutions are functioning under the auspice of provincial governments for the children with different disabilities. Recently, the special education institutions which was run by the federal government, have been devolved into provinces due to 18th amendment of the Constitution of the Islamic Republic of Pakistan (Ahmad &Yousef, 2011).

Table 2: Special Education Centres/ Institutes in Pakistan

S.No	Names and Location
1	National Special Education Centre for VHC, Islamabad
2	National Special Education Centre for HIC, Islamabad
3	National Special Education Centre for PHC, Islamabad.
4	National Special Education Centre for MRC, Islamabad
5	National Institute of Special Education, Islamabad
6	National Training Centre for Special Persons, Islamabad
7	National Library and Resource Centre, Islamabad
8	National Braille Press, Islamabad
9	Vocational Rehabilitation and Employment of Disable Persons (RU), Islamabad.
10	Vocational Rehabilitation and Employment of Disable Persons (Service Centre-I), Islamabad.
11	National Mobility and Independence Training Centre Islamabad.
12	Provision of Hostel Facilities at NSEC (VHC) Islamabad

Source: (Directorate General of Social Welfare, Islamabad, 2015)

As far as the availability of special education and training are concerned, they are provided according to the types of disability. Though, the number of such services is less as compared to the prevalence of disability which is high among children. As a result, they are vulnerable to disease and death. Such situation are very alarming in rural area of Pakistan due to lack of safe drinking water, sanitation, and health services (Mitra *et. al.*, 2012).

Directorate General of Special Education is an attached department of Capital Administration & Development Division and following centres/ institutions are running under its administrative control:

The Directorate of Special Education has enough staff as well as sufficient funds. The staff comprises of administrative as well as service providers, including social case workers, special education teachers, therapists and doctors which constituted a total of 621 employees from grade one to 20.

Children with different special needs availed different services from these special education schools. The number of these beneficiaries is given below:

Table 3: Beneficiaries of Special Education Centers (2013 – 14)

S. #	Name of Centre/ Institution	No. of Students		
		Male	Female	Total
1.	National Special Education Centre for Intellectually Challenged Children, H-8/4	120	60	180
2.	National Special Education Centre for Hearing Impaired Children, H-9	314	211	525
3.	National Special Education Centre for Visually Handicapped Children, G-7/2	169	114	283
4.	National Special Education Centre for Physically Handicapped Children, G-8/4	228	149	377
5.	National Training Centre for Special Persons, G-9/2.	179	32	211
Total:		**1010**	**566**	**1576**

Source: Federal Directorate of Social Welfare and Special Education, Islamabad, 2015

Table 4: Frequency of Beneficiaries of the Special Education Institutions (2013-14)

S. #	Name of Centre/ Institution	No. of Beneficiaries
1	National Institute of Special Education	11351
2	National Mobility and Independence Training Centre	453
3	National Library & Resource Centre	24000
4	National Braille Press	1220
5	Vocational Rehabilitation & Employment of Disable Persons	14960
6	Orthopedic workshop , Special Education centre for PHC	785
	Total	**52769**

Source: Federal Directorate of Social Welfare and Special Education, Islamabad, 2015

These Directorates provide special needs training to the disable children according to their needs.

3.11. Functions of Special Education Centres/ Institutions

The special education centres are responsible for the assessment, diagnostic, and referral services of children with special needs. Besides diagnostic services, these institutions also render educational and training service to children with special needs as well as the special education teachers and professionals. For instance, children with special needs receive academic and vocational training, and different types of therapies such as physical and speech therapies. Similarly, there are training centres in the same directorates which provide training to the special education teachers, counsellors, and other service-providing professionals.

Summary

As far the services for children with special needs are concerned, there is a network of special education centres at the federal level. These institutions were

established in 1982 and controlled by the Federal Directorate General of Special Education, Pakistan. There are eleven special education centres working under the directorate. As far the funds and structure of special education are concerned, there are ample funds available for special education services. Moreover, employees of the special education centres at the federal level enjoy a well-structured job with full facilities and entitlements as compared to Khyber Pakhtunkhwa.

3.12. Social Welfare, Special Education and Women Empowerment Department Khyber Pakhtunkhwa, Pakistan

The Department of Social Welfare was created as a separate administrative unit in 1995 to frame policies for the welfare of the neglected, marginalized, and vulnerable segments of society. However, since then the department failed to achieve these objectives and is still considered as a very weak department as compared to the federal directorate of social welfare and special education, as discussed above.

One of the reasons was that this department went through administrative changes from time to time, for instance, Women Development was initially attached with Social Welfare Department but was made part of Population Welfare Department on June 06, 1996. However it was re-attached with Social Welfare Department in November 2001. In the post 18th Amendment scenario, the department was renamed as *Zakat, Ushr,* Social Welfare, Special Education & Women Empowerment Department on August 16, 2011.

Theoretically, the department is considered as one of the significant and major departments in official documents, however, on ground, the situation is extremely worse in terms of service delivery and administrative functions. This department is responsible for administrative functions such as planning, coordination, and implementation of

policies as well as various social welfare services to the destitute segments of society (Government of Khyber Pakhtunkhwa, 2013).

Similarly, the Directorate of Social Welfare has two setups of organizational structure. One is known as the top management of social welfare which is also called the 'Secretariat Level staff' who are responsible for policy formulation while the other is 'Directorate Level staff' who are responsible for implementation of the policies and service provision. The organisational structure of the staff is as given below:

This huge setup is struggling to create awareness among people, explore community resources, promoting remedial, curative and rehabilitative services for destitute segments, establishing welfare homes, rehabilitation of drug addicts, coordination and implementing of international conventions. However, the findings of this study (see chapter 6 of this research) reflect that the department or directorate of social welfare is unable to achieve the above-cited objectives due to lack of political well, scarce financial resources, lack of job structure, and effective and holistic social welfare policy.

3.11. Number of Social Welfare Institutions in Khyber Pakhtunkhwa

The Department of Social Welfare and Special Education provides, as described below, various social welfare services to different segments of society such as welfare and rehabilitation of the destitute, women in distress, drug addicts, persons with disabilities, and working women.

The Department of Social Welfare and Special Education, in addition to the above centres, also provides services to mentally retarded and physically handicapped children. It has, hence, seven such centres in Khyber Pakhtunkhwa who are supposed to provide formal education, vocational and skill training. There are seven such centres, which provide education and rehabilitative services to children with intellectual and

physical disability. Such rehabilitative services consist of formal education, vocational, and skill training.

Table 5: Frequency of Social Welfare Institutions in Khyber Pakhtunkhwa

S.No.	Type of Institutions	No. of Institutions
1	*Dar-ul-Kafala*	4
2	*Dar-ul-Aman*	6
3	Working-Women-Hostel	12
4	Half-way House	1
5	Mentally Retarded and Physically Handicapped Center	7
6	Deaf & Dumb School	10
7	Govt, Institutes for the Blind	7
8	Drug Addicts and Rehabilitation Center	5
9	Welfare Home for Children	8
10	Artificial-Limbs-Workshop	1
11	Industrial-Training-Dastkari-Centre	172

Source: Directorate of Social Welfare Khyber Pakhtunkhwa, Peshawar

Besides centres for children with intellectual and physical disabilities, such centres also provide different services to children with hearing disability. There are ten such special education schools for the deaf & dumb children, nine for male while one for female, which provide formal education through sign language, charts, and models. In addition to education, they receive various vocational trainings such as sewing, cutting, knitting, and embroidery. These institutes also provide medical, free uniform, and transport facilities.

Moreover, this institute provides primary level braille education, canning skills, hostel, and transport facilities, free books and uniform to children with visual disability (Directorate of Social Welfare, KP, 2016).

Similarly, along with service providing institutions, the department is also closely associated with planning and policy making bodies such as Provincial Council for Social Welfare (PCSW) and Provincial Council for the Rehabilitation of Disable Persons (PCRDP).

The Provincial Council for Social Welfare (PCSW) is an important body of social welfare which was constituted in the year 1974, and re-structured in the year 2000. The Minister of Social Welfare and Women Development, Khyber Pakhtunkhwa, is the chairperson while Director Social Welfare, Special Education and Women Empowerment is the secretary of the Council. It formulates and implements plans and policies for promotion of social welfare activities. It also provides financial assistance to registered social welfare organizations, and helps organizing seminars, conferences and workshops. However, practically, this body is completely invisible and dysfunctional in the province; consequently, there is no check and balance on the performance of NGOs and, most importantly, no effective policy for social welfare institutions, especially for children with disability.

Similarly, PCRDP was established in pursuance of Section 5 of Disable Persons (Employment & Rehabilitation) Ordinance 1981 to perform various functions. It is responsible for the execution of policies made by the NCRDP. Furthermore, it rehabilitates persons with disability by provision of different aids such as wheelchairs, try cycle, white cane, etc. It also provides financial assistance to NGOs working for the rehabilitation of persons with disability and also helps in implementation of 2 % quota in public and private sector organizations for the special people.

3.12. Re-structuring Social Welfare and Special Education in Pakistan: Post-constitutional Amendments Scenario (also known as 18th Amendments)

The sector of Social Welfare, as referred to above, was working in two administrative setups in the country, one was working at federal level while the other was at provincial level. Both sectors worked independently. As far the efficiency and effectiveness of both setups was concerned, social welfare at federal level was more

effective due to the provision of sufficient funds and a better job structure while the provincial setup was poorer in terms of performance as well funds and job structure. In 2011, changes were brought in the Constitution of 1973 of Pakistan which are also known as 18th amendments. According to these amendments, the federal institutions working in the four provinces of Pakistan, were devolved to the provinces in 2011. Hence, those social welfare and special education centres which were previously working under The Federal Directorate of Social Welfare were handed over to Khyber Pakhtunkhwa like the rest of the provinces. This was an unhappy decision which has badly affected the sector of social welfare (see Views of the Official regarding these amendments in Chapter 6 of the thesis).

In Social Welfare & Special Education, sixteen Centres / Institutes located in Khyber Pakhtunkhwa have been transferred to Provincial Government along with the 450 employees. Similarly, there were four centres, one each at district *Abbottabad, Kohat, Swat, & Peshawar,* funded by PSDP were also transferred with the staff of 40 members.

Summary

The Directorate of Social Welfare and Special Education was initially working at the federal level only. However, it was extended to provincial level in 1970 to frame policies for the welfare of the neglected, marginalized, and vulnerable segments of the society. Initially, social welfare was an attached department of Women Development, Population Welfare and *Zakat* and *Usher*. These setups were established as independent departments in the province running under their directorate.

Currently, the Directorate of Social Welfare is divided into two organizational structures, i.e. "Secretariat Level staff" who are responsible for policy formulation while the other is "Directorate Level staff" who are responsible for implementation of the

policies and service provision required for addressing the socio-economic needs of under-privileged segments of society such as children, aged, women, disable etc.
In line with its mandate the Department has established eleven such institutions for the welfare and rehabilitation of the destitute, women in distress, drug addicts, persons with disabilities and working women.

However, such a huge set up and organizational structure fail to provide relief to children with special needs in general and intellectually disable in particular. As the system of social welfare is based on the philosophy of 'residual model of social welfare" which means that those echo their voice for the social welfare services, they will be benefit while those who does not will remain deprived.

CHAPTER 04 METHODOLOGY

Chapter 1 explained the overall nature of this research, its rationale, significance and its organization while Chapter 2 elaborated the concept of disability, intellectual disability and the literature on the effects of intellectual disability on families. The underlying aim of the respective chapter was to understand the effects of ID on the families in broader perspective, and also to provide a theoretical foundation for the interpretation of the study's findings. Likewise, Chapter 3 was concerned with evaluating the existing social welfare system in the country in order to point out lacunas in the social welfare service from the perspective of children with intellectual disability in Pakistan. While the current chapter describes the way this research was carried out to answer the questions raised and the objectives set.

This chapter also explains the methodological position of the study and procedures employed for carrying out this research as per the study objectives. Methodology in social research refers to "the techniques and epistemological pre-suppositions which contribute to how data is collected and analysed in relation to a research problem" (Gilbert, 2001: 220). It considers the ways in which the data, on which the researcher bases his or her findings, are produced. Methodological concerns are informed by particular worldview, an assessment of the nature of the subject to be researched and the sorts of material that are available to research the problem. "The selection of a methodology is crucial for the project, as it will, to a certain extent, determine the nature of the findings" (Gilbert, 2001: 221).

4.1. Purpose of the study

Fundamental to the research process is the formulation of research purpose and objectives. These provide direction and framework for the research in the field (Francis,

2000). Research purpose is the target a researcher wants to achieve by the completion of the research journey (Hussain, 2009). Hence, a thoughtful deliberation is needed during this stage. According to Locke, Spirduso, and Silverman (2000: 9), the purpose statement indicates "why you want to do the study and what you intend to accomplish". Such puzzles normally arise philosophical questions, such as ontological, epistemological, and methodological status of the study.

In qualitative research, there are certain philosophical guidelines which guide one's approach. These include the ontological, epistemological, and methodological aspects of the study. In social research, ontology refers to perspectives on reality (Hudson and Ozanne, 1988: 508-521). In qualitative research, it is believed that reality cannot be discovered like quantitative paradigm rather it can be interpreted in participant perspective in a naturalistic context (Ibid: 508). Moreover, qualitative research is naturalistic, based on relativist epistemology. Epistemology refers to the relationship of researcher and researched (Carson *et. al.*, 2001). Hence, the ontological direction in this research is to find out what effects a child with ID exerts on families in Khyber Pakhtunkhwa. As far the effects are concerned, these are social effects, economic effects and psychological effects, while, epistemology touches the question of why studying and exploring effects of child with ID and how it can be measured such as who would be suitable persons/people who could share these realities. No, doubt, the family members such as parents including mothers, fathers, siblings, grandparents , and others can share their views, experiences, problems, and perceptions etc. Hence, how these perceptions and experiences can be studied create certain methodological questions. Keeping in view the nature of the subject, this study follows qualitative research methodology which is based on interpretative-phenomenological philosophies which employ qualitative methods such as In-depth Interviews, Focus Group Discussions (FGDs) and

Observations. These tools are useful for yielding contextual and participant-oriented information.

This research aimed to discover various effects of children with ID on family members. This study also seek views of parents having children with ID at selected districts of Khyber Pakhtunkhwa. Similar effects, as referred to above, have also been revealed by different studies (Farber, 1959; Toris and Irma, 1987; Inam and Zehra, 2012; Roos, 1977), however, as with regard to Khyber Pakhtunkhwa (Pakistan), there is no such study available. Hence, this study is the first of its kind to address the issue in sociological perspective.

This study is also supposed to explore the role of special education centres and social welfare departments in mitigation of parents' miseries, hence, the views and experiences of officials of the special education are also included.

This research is based on the decision-driven or problem-solving model of social work which enables the policy makers to formulate an effective social policy for the children with ID and the affected parents and families in order to integrate them in society and help them cope effectively with their extra burden and liabilities.

4.2. Locale of the target area

The next stage was the identification and determination of the target areas. To find out the centres/institutes working for the children with intellectual disability, I consulted the Directorate of Social Welfare and Special Education at *Peshawar* and obtained regarding the working areas and the nature of activities. The centres/institutes work in seven areas comprising four districts, namely, *Peshawar, Nowshera, Mardan* and *Haripur*. There are seven (7) such institutes located in six districts out of 26 districts of Khyber Pakhtunkhwa. In the 1st phase, data was collected from the 3 institutes located

in districts *Peshawar* and *Haripur*; thereafter, in the second phase, the data was collected from five (5) institutes located in four (4) districts.

Table 6: Centres/Institutes of Special Education Schools for Children with Intellectual Disability in Khyber Pakhtunkhwa

S.N	Name of Centre	Male	Female	Total
	PESHAWAR			
1.	Section for Mentally Retarded Children, Special Education Complex, Phase. V. *Hayatabad, Peshawar*	55	25	80
2.	Centre for Mentally Retarded and Physically Handicapped Children, *Bashir Abad, Peshawar*	31	11	42
	CHITRAL			
3.	Centre for Mentally Retarded and Physically Handicapped Children, Zargarandeh, *Chitral,* 0943-413094	38	12	50
	MARDAN			
4.	Mentally Retarded Children, Special Education Centre, *Mardan*	42	10	52
	BANNU			
5.	Centre for Mentally Retarded and Physically Handicapped Children, *Bannu*	41	-	41
	HARIPUR			
6.	Centre for Mentally Retarded and Physically handicapped Children, *Haripur.*	80	29	109
	NOWSHEHRA			
7.	Centre for Mentally Retarded and Physically handicapped Children, *Nowshehra*	31	11	42

Source: Based on data collected from two special education centres namely Hayatabad Special Education complex and Centre of Mentally and Phys8cally Retarded Children, Bashir Abad, Peshawar, during Nov-Dec, 2012.

4.3. Procedure of Selecting Respondents

This study consisted of two types of respondents, one were the parents and family members of children with intellectual disability enrolled in the centres while the other were officials of the centres and institutes. For an easy understanding, this chapter is divided into three parts: part 1 deals with the selection of parents and family members; part 2 reflects upon selection of officials; part 3 reflects on the implication of this research for the society.

Part 1

4. 3.1. Selection of Parents and Family Members

For deciding about the selection of parents as respondents, lists of enrolled children with ID were obtained from each special education centre. Such parents and family members, according to the official and social case workers, were the active parents who make regular contact with institutions and attend parent-teacher meeting. However, the selection of the parents was made by keeping in view the socio-economic diversity of such children and their parents, birth order, level of education, source of income, economic status, type of marriage, and birth place of the child. These diversities were ensured after thoroughly discussing each respondent with the social case worker, manager of the institute, and special education teachers who have complete information about their family condition. These parents were selected from the list of following institutions:

1. Section for Mentally Retarded Children at Special Education Complex *Hayatabad*
2. Centres for Physically and Mentally Retarded Children, *Bashir Abad, Peshawar.*
3. Centre of Physically and Mentally Retarded Children, *Haripur.*

Thirty (30) parents were purposively selected from the list of institutes located in the districts of *Peshawar* and *Haripur* (15 parents from each district). In-depth interviews were conducted with them. Along with Individual Interviews, 4 Focus Group Discussions (7 participants in each FGD) were also conducted with the parents to get a more valid and reliable information. Hence, a total of 58 parents were interviewed for this purpose. Similarly, to explore the role of institutes in mitigation of the miseries of parents, officials of the institutes were also interviewed. For this purpose, 15 In-depth Interviews were conducted with officials selected from the 5 institutes located in 4

districts of Khyber Pakhtunkhwa i.e., District *Peshawar*, District *Nowshera*, District *Mardan* and District *Haripur*.

Table 7: Types of Respondents (Parents)

S.No	Respondents from each Institute in each Dist.	IDIs	FGDs (total 4 FGDs held) With 7 participants in each FGD
1	Parents/Family members from Special Education Centre, *Hayatabad, Peshawar*	07	07 (1 FGD)
2	Parents/Family members for from Centre for Physically & mentally Retarded Children, *Bashir Abad, Peshawar*	08	07 (1 FGD)
3	Parents/Family members from Centre for Physically & mentally Retarded Children, *Haripur*	15	14 (2 FGD)
	TOTAL	30	28

4. 3.2. Rationale for Selection of Institutes and Parents/Family Members of Children Having ID

As the study was related with the effects of children with ID on the family, for this purpose, family members such as mothers, fathers, and other family members (brothers, sisters, grandparents, and aunts/uncles who resides with them) were the key subjects or participants of the study and they were selected from the official lists of enrolled children in these institutes. However, the selection of parents was made by keeping in view the socio-economic and demographic characteristics of respondents (see its detail in Table 7, 8, 9).

4.3.2.1. Selection of the Centres

The reason for selecting the institutes/centres for selection of respondents was practical and resource-based which refers to accessibility to the population easily and developing insight into the experience of the subjects or participants (see Mason, 2002). Qualitative research is all about depth, nuance, and complexity, and understanding of the phenomena rather viewing 'census' (Ibid). Hence, it was easy for me to travel to the area frequently without any hurdles and spent ample time in the field. Furthermore, it was

financially manageable for me as there was no funding available for this study. Furthermore, the number of children with ID admitted in the centres/schools located in district *Peshawar* and district *Haripur* were greater as compared to other places. Moreover, these areas were selected for ensuring diversity in participants' socio-economic and cultural characteristic as people in district *Peshawar* were mostly *Pashto* speaking while in District *Haripur*, *Urdu* and *Hindko* speaking, which was another reason behind these selections.

Hence, districts *Peshawar* and *Haripur* were purposively selected. The idea behind purposefully selection of participants or sites was to facilitate the researcher and understand the problem and the research question (Creswell, 2003). According to Miles and Huberman (1994), purposive selection of participants and sites needs to cover setting (where the research takes place), the actors (who is observed or interviewed), the events (what the actors are observed doing or saying), and the process (the evolving nature of events undertaken by the actors within the setting) (Ibid: 85).

4.3.2.2. Socio-Economic Status of Parents

For maintaining validity and reliability in research, appropriate tools of data collection and diversity in selection of respondent is necessary, for yielding appropriate information is the purpose of qualitative research (see Brink, 1993: 35). Besides other important factors, keeping in mind the socio-economic status of subjects or participants is also extremely necessary. Validity determines whether the research truly measures that which it was intended to measure or how truthful the research results are (see Jopps, 2000: 1) while reliability in qualitative study can help us "understand a situation that would otherwise be enigmatic or confusing" (see Eisner, 1991:58). In qualitative research, with a purposive non-random sample, the number of people interviewed is less important than the criteria used to select them (see Wilmot, n.d: 221) the characteristics

of individuals are used as the basis of selection, most often chosen to reflect the diversity and breadth of the sample population.

For maintaining diversity in information, keeping in mind the socio-economic status of subjects or participants, is necessary. For this purpose, the selected respondents were divided into three economic statuses, i.e. lower (48 %), middle (25 %) and upper (17 %) (See Table 8, 9, 10) because such effects may vary for parents having a different socio-economic status. Furthermore, the indicator for determining the economic status was monthly income with the number of dependents, ownership of house, and residential locality. Similarly, those having monthly income from Rs.7000 to 12000 with dependent of more than 5 persons were placed in lower class (8%), 30,000 to 40,000 with at last 5 dependents in middle class (25%) and those who have 50,000 and above with minimum dependents of 5 were placed in upper status (17%). Besides, monthly income, those who lived in their own houses located in urbanized area like *Hayatabad, Gulbahar* etc. were further indicators for determining the upper class.

4.3.2.3. Age of the Children with ID

The selection of the parents was also based on the age of the children with ID. The age of children put different challenges for the parents, for instance, children with early age needs more care and support, while grown-up children need extra primary care, mobility issues, and abuses in society. For this purpose, such children were divided into four categories on the basis of their age: parents having children from (3-6 years) constituted 22 %; similarly, (7-10 years) constituted 31 %; (11- 14) constituted 24%; and (15- 18 years) constituted 22 % of the total participants.

4.3.2.4. Nature and Type of ID

Nature and type of ID of these children were determined from the already existing criteria used by the schools/institutes for assessment during the admission process.

Therefore, the officials have categorized children in three major types of ID i.e. severe ID, moderate ID, and mild ID. According to them, severe ID are those in which the child have IQ less than 35%. Such children show hyper-activity and problem in communication and mobility, like Cerebral Palsy, Autism with hyper activity, hydro & micro cephalic. Similarly, children with moderate ID were those who have IQ between 35 and 50. Such children need training in development of basic social skills like eating, interacting with other people, and mobility. However, they cannot get education beyond primary level due to their limited IQ level. Furthermore, mild categories were of 50 to 70 IQ; such children can be educated up to higher level but with special provision of education. Furthermore, such persons can work, live and travel independently but will need support and help to handle money and to plan and organize their daily life.

4.3.2.5. Family Structure and Residence Pattern

Family structure and location of residence was an important indicator for selection of participants. There are two family structures existing in area i.e. joint and nuclear. Joint family is a larger social group of kinship which consists of parents and their children residing with grandparents, cousins, and others related by blood (NesSmith, 1995), while, nuclear family is a smaller social group consisting of parents and their unmarried children (Macionis, 2012). The purpose of selecting family structure was to study the effects of ID on different family structures. In joint family structure (58%), the primary care giver may feel relaxed due the support of other family members, while, in nuclear family (42%), there may be less support due to small family members.

4.3.2.6. Gender Equality

For ensuring gender equality in selection of participants, both mothers and fathers were selected equally to understand the feelings and experiences of both parents,

hence, 44 % of fathers and 42 % were mothers were included in the study. Similarly, an equal ratio of children with ID from both the genders was maintained.

4.3.2.7. Family Members like Grandparents, Paternal/Maternal Uncles/Aunts and Siblings

In joint family structures, other family members constitute an important part. They extended social and economic support to the parents of these children. Besides parents, grandmothers (8%) and uncles (12%) have also been included in the study to know their views and experiences of the impact of these children on the family.

Table 8: Relationship of Research Participants with Children having ID

Interview/FGD with care-givers	Frequency	Percentage (%)
Mothers	20 (5 working mothers which constitutes 25%)	34
Fathers	26	44
G. Mothers	5	8
Uncles/Siblings	7	12
Total	58	100

Table 9: Demographic Profile of Child with Intellectual Disability

Gender of Child WID	F	%	Age				Birth took place		Relationship of parents	
			3-6	7-10	11-14	15-18	Home	Hospital	Cousin	Outside family
Boys	49	84	11 (22%)	14 (27%)	12 (25 %)	12 (24 %)	33 (67%)	16 (32%)	29 (60%)	20 (40%)
Girls	09	16	02 (22%)	04 (44%)	2 (22%)	01 (11%)	06 (66%)	03 (33%)	06 (66%)	03 (33%)
Total	58	100	13 (22%)	18 (31%)	14 (24%)	13 (22%)	39 (67%)	19 (33%)	35 (60 %)	23 (40%)

Table 10: Family Structure and Economic Status of Participants

Gender of Child WID	F	%	Family structure		Financial Status of Parent			
			Nuclear	Extended	Upper	Middle	Lower-Middle	Extremely poor
Boys	49	84	21 (42 %)	28 (57 %)	08 (16 %)	13 (26 %)	25 (48 %)	03 (6 %)
Girls	09	16	03 (33 %)	06 (66 %)	02 (22 %)	02 (22 %)	03 (44 %)	02 (22 %)
Total	58	100	24 (42 %)	34 (58 %)	10 (17 %)	15 (25%)	28 (48%)	05 (8 %)

Part. II

4.4. Selection of Officials

Besides parents, staff members of the special education schools and centres are the important stakeholders in treating and training these children. The staff members were included in the study to know the nature of services provided by them for mitigating the miseries of parents. Similarly, these staff members were also acting as 'gatekeeper' for approaching to the parents of these children.

Fifteen (15) officials including Social Case Workers, Therapists, Teachers and, Heads of the institutes were selected purposively from these institutes for interviews (see Table 11). Initially, officials were selected from three Centres i.e. two from District Peshawar and one from District Haripur for interviews as the researcher was already interviewing parents and family members in these centres. However, after completion of data presentation of parents' views, the interpretation of data of officials was started; it was found that the data is deficient as it is not reflecting the actual role of the institution. Hence, my research advisors asked me to collect further data on the institutional role in mitigation of miseries of parents. It was very difficult to seek permission from the Director Social Welfare once again before the start of field work as entry into these institutes was not possible. Fortunately, I got their permission and started data collection process once again. In this phase of data collection, I decided to visit the most advanced special education centre and rehabilitation institution located in the capital of the Pakistan i.e. Islamabad, before meeting with officials in the province. The purpose of these steps was to develop a conceptual framework of model institutions and services. I selected two Centres after consultation with the Director Special Education Islamabad—who had been my senior fellow at the Department of Social Work in early 80s, hence, he extended his cooperation wholeheartedly. The two centres I selected were Autism

Resource Centre (ARC) located in Rawalpindi and National Special Education Centre for Mentally Retarded Children, Islamabad. The former Centre was privately run by charities and donation while the latter one was run under the Federal Ministry of Social Welfare and Special Education, Pakistan. Later on, five special education Centres for Physically & Mentally Retarded Children were selected purposively from the list of the Directorate of Social Welfare & Special Education, Khyber Pakhtunkhwa (see detail in Table 12).

Details and names of the institutes are given below.

1. Section for Mentally Retarded Children at Special Education Complex *Hayatabad*
2. Centres for Physically and Mentally Retarded Children, *Bashir Abad, Peshawar*
3. Centre of Physically and Mentally Retarded Children, *Nowshehra*
4. Section for Mentally Retarded Children at Special Education Complex, *Sheikh Malthoon, Mardan*
5. Centre of Physically and Mentally Retarded Children, *Haripur.*

Moreover, fifteen officials including Social Case Workers, Therapists, Teachers and Heads of the institutes were selected purposively for interviews. In-depth Interviews were conducted with them. Moreover, participant observation was also administered during data collection process and the condition of equipment and other services were captured through snaps. The interviews were recorded through audio recorder device. Thereafter, interviews were transcribed, analyzed, and themes were developed.

Table 11: Types of Respondents (Officials)

S.No	Type of Respondents	Frequency
1	Head of Institution	5
2	Teachers	5
3	Physiotherapists	3
4	Social Caseworkers	2
	TOTAL	15

Table 12: Names of Institutes/Centres, types of officials interviewed, and number of officials

S.#	Name of Institute/Centre	Officials Interviewed	No. of Interviews
		Islamabad/Rawalpindi	
1.	Autism Resource Centre (ARC)	i. Clinical Psychologists/Speech Therapists ii. Director of ARC iii. Chief Executive Officer ARC	3
2.	National Special Education Centre for Mentally Retarded Children	i. Director ii. Special Education Teacher	2
Total Interviews			05
		Khyber Pakhtunkhwa	
1.	**District Peshawar** Section for Mentally Retarded Children at Special Education Complex Hayatabad	i. Director ii. Physiotherapists iii. Special Education Teacher	03
2.	**District Peshawar** Centres for Physically and Mentally Retarded Children, Bashir Abad, Peshawar.	i. Senior Manager ii. Physiotherapists iii. Special Education Teacher	03
3.	**District Nowshehra:** Centre of Physically and Mentally Retarded Children, Nowshehra	i. Manager ii. Physiotherapists iii. Special Education Teacher	03
4.	**District Mardan:** Section for Mentally Retarded Children at Special Education Complex, Mardan	i. Director ii. Physiotherapists iii. Special Education Teacher iv. Social Case Worker	04
5.	**District Haripur:** Centre of Physically and Mentally Retarded Children, Haripur.	i. Manager ii. Special Education Teacher	02
	Total Interviews		15

4.5. Salient Features of the Study Area

Among the four provinces of Pakistan, Khyber Pakhtunkhwa (KP) is the smallest in terms of area (UNDP, 2011) with population of 17.7 million (Census Report, 1998) where predominantly populated by *Pakhtuns* and about one third of the population are non-*Pakhtuns*. Currently, the estimated population of KP is 24.7 million (UNDP, 2011). KP is the third most populated province of Pakistan where more than half the population lives in the mountainous and arid areas. Patriarchy is the dominant social feature of *Pakhtun* society where male members is the dominant families member compete with each other to control access to land and resources through kinship networks (Ali, 2005:

58). While there are slight variations in the observance of *purda* (veiling), women were restricted to domestic activities due to gender segregation and patriarchy (Hussain *et. al.*, 1997; SRSP, 2001c). As Ali notes in his study of women's status in such areas, "women's place is in the home... the job-market lies within the public sphere which is a male domain, and a 'good' women stay within the *Chardiwari* [household boundaries]" (Ali, 1998a: 141). As result, women are normally deprive from education, health and other available facilities (Ali, 2000; Ali, 1998b).

Unfortunately, the people of KP have been adversely affected by the influx of refugees fleeing across the border from Afghanistan in 1979. Consequently, around 1.5 million refugees resides in KP today. Moreover, a fresh wave of militancy erupted in 2004 in the wake of war against terrorism which had badly affected the province due front line province (Ali. n.d: 6). Furthermore, the province has been struck twice by major natural disasters i.e. the earthquake of October 2005 which caused damages of Rs. 58.7 billion to the province (Asian Development Bank (ADB) and World Bank. 2005).

4.6. Interpretivist-phenomenological Approach

Every research has two basic objectives: first to fill the gap in the already exiting knowledge (see Brown and Duguid, 1991; Tsoukas and Valdimirou, 2001; Orlikowski, 2002) and to seek a solution for a problem which is also called as problem-solving model. To achieve these goals, the research has to adopt either positivist approach or interpretivist approach. The purpose of both approaches is to study reality accordingly. As the positivist approach sees reality objectively which can be measured through quantitative tools such as a survey for knowing the cause and affect relation, while interpretivists see reality as a subjective phenomenon which can be interpreted in a certain context through different sources. Hence, these approaches touch upon philosophies such as ontology, epistemology and methodology for more clarity.

Ontological philosophies revolve around the "what", i.e., what is reality? This can also be explained in a way that what is actually the problem, for instance, what is the effect of a child with ID on families? Similarly, ID have never been studied sociologically in the research area, consequently, it has never been posed as a social problem. As a result, the child and family bear the burden of such problems alone without the support of society. Such debates touch the boundaries of ontological philosophies. When this philosophical justification is given, then, a question of suitable methodology arises. That is why for unearthing the effects of the existence of a child with ID on the family, a blend of methodological approaches called as Interpretivist-phenomenological approach was employed for this research.

There are two types of phenomenology such as hermeneutic phenomenology which refer to the approach in which a researcher interprets texts to explore lived experience (see Kafle, 2011). For example, what is patient's experience being treated for cancer as interpreted through blogs and tweets? While the other type is called as transcendental phenomenology, which refers to people's meaning of a lived experience of a concept or phenomenon (Mingers, 2003). The purpose of transcendental phenomenology is to describe the essence, the nature, of experiencing a phenomena (Mingers, 2003; Merriam, 1998).

As this study aims to study socio-economic and psychological effects of child with intellectual disability on families, hence, the life experiences of parents, especially mothers were explored by using triangulated methods such as observation, interviews, and group interviews. The researcher in this study followed emic epistemological approach. Hence, this blended approach enabled the researcher to clarify the ontological and epistemological position of this research which aims to capture/understand the concept of intellectual disability, its effects on the family from the parents' perspective

(ontology) and the methods applied for attainment of parents' views and experiences and institutional role in mitigation of parents' miseries (epistemology).

4.7. Tools of Data Collection

The researcher employed semi-structured interview guide for data collection in this study. Such tool is normally best for a focused interview (Gilbert, 2001). It contained both open and closed ended questions. The nature of semi-structured interviews and its justification for being employed for the current study is further explained below.

4.7.1. Semi-structured Interviews

Interviews are "a widely used tool to access people's experiences and their inner perceptions, attitudes, and feelings of reality" (Zhang & Wildemuth, 1992: 1). Based on the degree of structuring, interviews can be divided into three categories: "structured interviews, semi-structured interviews, and unstructured interviews" (Fontana & Frey, 2000:695). As far as structured interview is concerned, it is "an interview that has a set of predefined questions and the questions would be asked in the same order for all respondents" (see Fowler and Mangione, 1990:696). This standardization is intended "to minimize the effects of the instrument and the interviewer on the research results" (see Oppenheim, 1992: 371). Structured interviews are "similar to surveys, except that they are administered orally rather than in writing" (Fontana & Frey 2000: 645; Silverman, 2000, 2006).

This research used semi-structured interviews as a qualitative research method for data collection. As such interviews are particularly useful for getting the story behind a participant's experiences such as parents and family members who have shared their views and experiences regarding the effects of child with ID (McNamara, 1999).

Such interviews are also known as formal and informal conversation, in-depth interview, semi-standardized interview and ethnographic interview. It is also known as "semi-standardized or focused interviews in which the interviewers simply have a list of topics which they want the respondent to talk about, but are free to phrase the questions are they wish, ask them in any order that seems sensible at the time, and even join in the conversation by discussing what they think of the topic themselves" (Gilbert, 2001: 124).

4.7.2. Participant Observation

Observation is defined as "systematic description of events, behaviors, and artifacts in the social setting chosen for study" (Marshall and Rossman, 1989). Besides other tools, participant observation was also employed for obtaining more reliable and authentic reflections of family and parent's experiences having children with ID. This method was used for observing the overall environment of the institutes and available services for such children. The purpose of this tool was to study every aspects of the target special education schools, role of the officials and available facilities.

It is possible through this method to describe the overall dynamic of the field participant's point of view (Marshall and Rossman, 1989). As this study was based on the phenomenological philosophy, hence, relying on mere verbal expression sometime deceive the researcher. In order to obtain accurate information, the researcher used observation techniques as well. This enabled researcher to understand the prevalent situations well by using five senses, as it provide a "written photograph" of the situation under study (Erlandson, Harris, Skipper and Allen, 1993).

Participant observation as the auxiliary method employed during fieldwork of this research helped in collecting data in a natural setting.

4.7.3. Focus Group Discussion and Interviews

Besides individual interviews and observation employed for this research, Focus Group Discussion (FGD) was also used as method of data collection. FGD is a type of "in-depth interview accomplished in a group, whose meetings present characteristics defined with respect to the proposal, size, composition, and interview procedures" (Freitas, *et. al.*, 1998: 1).

The moderator facilitate discussion among participants in the group while participants influence each other through their answers to the ideas and contributions during the discussion (Gilbert, 2001). In this way, the group discussion produced data from transcripts, discussions, reflections and comments. According to Morgan, "the hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (Gilbert, 2001:166).

In this study, views and experiences were collected through individual interviews and observations, however, for developing consensus on the most common and important aspect of the effects of ID, FGD was selected as a tool for this purpose. FGD is also called as group interview or group discussion which involves exploration of ideas and interpretation of what people say (Barbour and Kitzinger, 1999). Focus Group contain 6 to 10 members who talk about a particular topic determine by the researcher (Gilbert, 2001). A facilitator or moderator facilitate discussion among participants. In general FGD lasted for one and half to two hours and were tape-recorded. Sometimes a video was made as well. The tape-recording was transcribed latter on for analysis. Four FGDs were carried out in each district. Among these four FGDs, two each were carried out with fathers two each with mothers.

4.8. Preliminary/planning Stage

Before starting field work, the researcher introduced the topic and objectives of the study to the official of the directorate such as Director, Special Education Teachers, Head of the respective institutions for seeking their confidence and permission as ethical responsibility. The Directorate issued letters to each district office with regard to my study and other necessary arrangements. Afterwards, I got engaged first with the two centres/Special Education centres located in District Peshawar and started observing their activities and carried out In-depth interviews. They have invited the parents for interviews on the request of the researcher. The initial interviews not only introduced me to the teaching and administrative staff of the centres but also to the parents and overall activities and processes. After being introduced to their activities and staff.

4.9. Commencement of Field Work

After planning and introductory sessions, I started visiting the centres according to the distance from my home station. For instance, in *Peshawar, Nowshehra and Mardan*, the field was not far from my home station and, therefore I was able to go there on a daily basis. On the other hand, I stayed for almost 10 days in District *Haripur* for collection of data as it was away from my home (170 km away), hence, staying in the field afforded exposure to virtually every aspect of the research problem. How I started this journey of field, it is necessary to discuss it in detail for the readers.

I started my field work from the Institute for Physically and Mentally Retarded Children at *Bashir Abad* one day prior to the data collection process in where I submitted the letter of approval issued by the Directorate of Social Welfare and Special Education, Peshawar. Thereafter, I set with the Manager and Social Case workers to identify the parents and family members for data collection process at the Institute. Hence, a list of almost 20 parents was prepared. Then, social case workers started

calling initially 4 parents for visiting the same institute for Individual Interview. After contacting and confirmation of the visit, I went back to my home station. I conducted the first interview with a parent with the support of the social case worker. Initially, I relied on staff members, however, after some days, I contacted the parents independently as per the prescribed list. However, I behave like student throughout the field work for getting maximum information in the form of views about child with intellectual disability and his/her effects on the family and their life. Moreover, I was able to visit the families of the children with ID, where they could openly share their miseries and the role of the Centre in rehabilitation of their children.

The interviews were started with the introduction and general discussion for creating a friendly environment before in-depth interviews and FGDs (see Ross, 1974). During the interviews, I provided maximum opportunity of talk to the participants (see Merton and Kendall, 2003), although I did interfere sensitively whenever I felt that the conversation was out of track.

Keeping in view the cultural values of our society, it was thought that a female assistant will be needed for both Individual Interviews and FGDs, however, upon discussion with the incharge of institute, he revealed that mothers and family members would never feel hesitation in interaction with me as they frequently visit these institutions and interact with the staff member who are mostly male, hence, the need for keeping a female assistant was less. Moreover, the topic of ID was so touchy for them that they wished to share their experiences with someone who could hear it in detail. Such interaction and exchange of information provided a source of psychotherapy for them.

I faced no problems in contacting women as the culture in Haripur area was not strict in respect to female participation in interview process.

Besides interviews, observation and taking field notes was also carried out and I tried to note carefully every relevant detail. I recorded key words for recalling in my subsequent writing up, either at the end of the day or whenever permitted. Thereafter, I transcribed that data which was immediately followed by interpretation.

4.10. Recording the Action: Field Notes

Recording what happens or is described by the participants during interviews, FGD or observation is the most important job of a researcher and the essence of social research. Such recordings are taking place in the form of full field notes, mental notes, and jotted notes (Emerson *et. al.*, 1995). Full field notes refer to the recording or writing up of observation promptly without any delay. Such notes are either tape-recordings which normally speed up the process but sometime are less reflective or hand written which is done immediately after interaction. Furthermore, mental notes are a skillful activity which develops with practice in which all the observation is recorded accurately of whatever happens in the field. Such skill is normally used in sensitive cases in which tape-recording or notepad could not be used. Jotted notes are useful when covert observation is taking place in some inconspicuous moments. Hence, all the aspects of the events or subjects is memorized and later on written in full notes (see Angrosino, 2005). During the field work, field notes were taken by using voice recorded during Individual Interviews and Focus Group Discussions which was transcribed and translated later on by the researcher. Furthermore, both metal notes and jotted notes were also taken during the process of observation both in the institutes and families where interviews and FGDs were held. Similarly, there were families who were not comfortable with tape-recording or notepad writing, hence, the jotted and mental note taking techniques were used.

3.11. Transcription, Interpretation and Data Presentation

After completion of interviews, the tape-recorded data was transcribed, hence, each interview was checked for the sound quality, and a precise record was prepared. It was indeed, a time consuming process to note down every information, however, by this way, the quality of data can be ensured (Burnard, Gill, Stewart, Treasure, and Chadwick, 2008). For preserving the data, I maintained separate folder at my laptop for individual interviews and focus group interviews. Thereafter, themes were developed from the transcribed data. However, during translating interviews from Pashto and Urdu into English, extra care was taken. Though, there is no exact equivalent exist in English for some words shared by the respondents, therefore, I translated them in simple words. This step was followed by analysis. So as to convey what the interviewees meant.

3.11. Thematic and Case-Oriented Analysis

This study followed thematic and Case-Oriented Analysis. Thematic analysis refers to identifying, analyzing, and reporting patterns (themes) within data (Boyatzis, 1998). It minimally "organizes and describes data set in (rich) detail, however, frequently it goes further than this, and interprets various aspects of the research topic" (Braun and Clarke, 2006: 79). The purpose of thematic analysis is to deduce something important related to research objectives (Braun & Wilkinson, 2003). Moreover, it reflects phenomenon from the participant's perspectives. The case-oriented method reflects an interpretive research philosophy that is not geared to identifying causes but provides a different way to explain social phenomena. For example, themes were developed first from stories obtained through a study conducted for understanding the feeling of victims of criminal gangs (Fischer and Wertz, 1979). Thereafter, themes were analysed and a contextual description were produced from that.

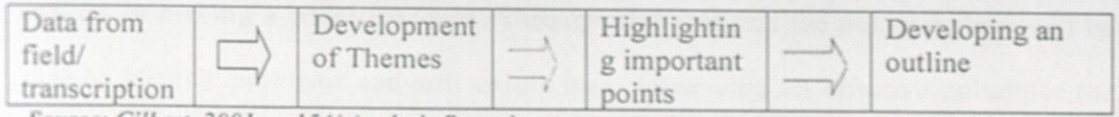
For conducting thematic analysis, the following 'six phases guide' is recommended,

> "1) Becoming familiar with the data, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Defining and naming themes, 6) Producing the report (Braun and Clarke's (2006: 77)"

3.11. Analysis Procedure:

The data was analysed based on the procedure given by Gilbert (2001:154). This procedure moves from field notes/transcripts to constructing outlines or re-sequencing. In between the researcher searches for categories/patterns and marking up the data (See Figure 1) for details.

Figure 1: Analysis Procedure

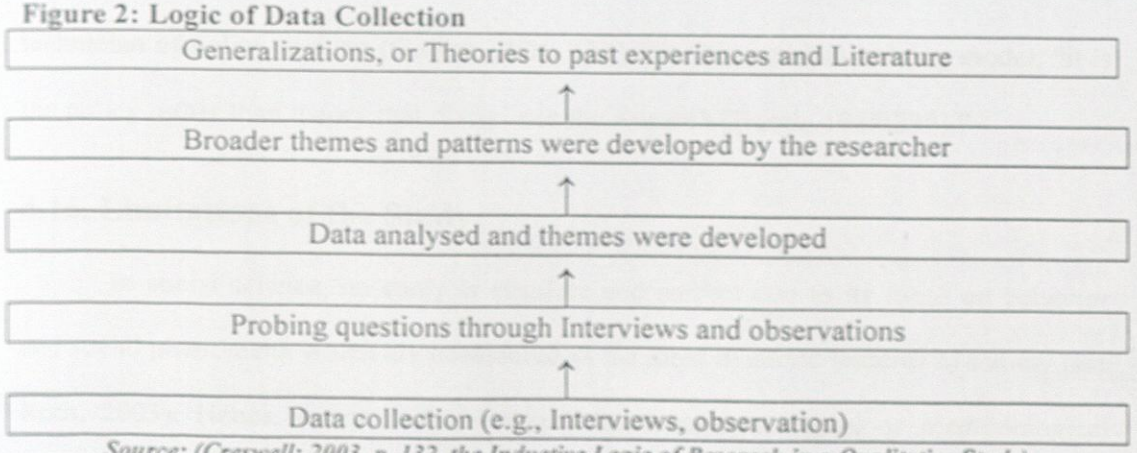


Source: Gilbert, 2001, p. 154/ Analysis Procedure

3.12. Inductive Logic Approach of this Research

For the present research, I followed Creswell's (2003: 132) approach on inductive data collection. This data collection process moves from general data to theories (see Figure 2 for details).

Figure 2: Logic of Data Collection



Source: (Creswell: 2003, p. 132, the Inductive Logic of Research in a Qualitative Study)

Part III

4.15. Decision-Driven or Problem-Solving Model: Practicability of This Research in the Field of Social Work

Research is purposeful activity, as referred to earlier in chapter 3 and devised for the achievement of set goals. Hence, it might be either for addition of new knowledge, seeking solution for a problem, political, ideological or policy enlightenment. These claims are devised in the form of models like "knowledge-driven model, the decision-driven model or problem-solving model, the political and the enlightenment model (Gilbert, 2001:133)."

So far the utilization of this research is concerned, it follows the decision-driven or problem-solving model which says that the research finding will guide the policy makers in making a policy decision. Through, this research the policy makers will be able to identify problems and will enable them to develop an effective policy for the children with ID and their family members. According to Weiss (1986), this model is based on an assumption that policy-makers and social researchers share a common understanding when it comes to defining social problems and recommending appropriate solutions.

According to this model, "the social scientists are a supplier of facts- the technician of policy-making (Gilbert, 2001: 134)." In this problem-solving model, "it is the policy rather than theory that disciplines the research (Booth, 1988:239)."

4.16. Limitations of the Study

In social science, no study is absolute and perfect due to its focus on behavior and social phenomena which are considered as the most dynamic features in society (see Roth, 2003). Hence, every study have got some epistemological or methodological deficiencies or limitations (Leedy and Ormrod, 2010), however, such limitations are

normally identified and put forward for the future researcher to be taken (see Simon, 2011).

In research terminology, limitations refer to the identification of potential weaknesses of the study (Creswell. 2003). Therefore, it is difficult to adopt absolutely perfect methods and strategies for covering everything of a social phenomenon. Hence, there were certain limitations, which may affect the quality of this study, some of them are given below.

- As this study was limited to few districts of the Khyber Pakhtunkhwa Province of Pakistan, hence, the small sample size selected for this study was the first limitation of the study. It would have been much better if a large sample size with more districts of Pakistan had been included, which would the make the study more authentic, however, owing to the interpretivist-phenomenology approach the study was restricted to a small sample size. Consequently, generalization may not be possible as the study focuses only on one province of Pakistan i.e. Khyber Pakhtunkhwa. Moreover, it would have been better if comparative study have been conducted for probing effects of children with ID on families in Khyber Pakhtunkhwa province as well of Punjab province, which could give a more holistic view of the problems. Furthermore, geographical, political and cultural reality may vary; therefore, this has covered few aspects of ID and institutional care. Similarly, the approach of the study may further be broadened by ensuring diversity in terms of cultural and geographical reality, for instance, what is the status of children and their parents in Punjab, Sind and Baluchistan? Even, other districts such as *Mardan, Chitral, Bannu*and the Tribal built of the country could be covered and the experiences of families in such far flung areas could be covered.

- It would have been better if a Psychological technique had been applied to know the mental growth of children with ID and mental health problem of their parents especially of mothers caused due to disability of their children. It would reflect the true picture of such effects especially in terms of psychological consequences.

4.17. Ethical Considerations

Ethical consideration refers to "the moral integrity of the researcher which is highly important feature of ensuring that the research process and a researcher's findings are trustworthy and valid (Mertens and Ginsberg, 2009:59)." The first and foremost ethical considerations in this study were informed consent. Informed consent refers "to informing human-subjects about the nature of research study, for which researchers obtain their consent prior to their participation in the study (Mertens and Ginsberg, 2009:60)." Thereafter, the researcher handover an inform consent form to participants which clearly reflects the aim and objectives of the study. After reading the consent form, their participation in the study is entirely voluntary and can quit any time.

Hence, in this study, initially proper permission was sought-out from the directorate by clearly mentioning the aim and objective of the study. Moreover, they were also informed about the participants of the study which were parents/family members and officials. Most importantly, the official of the concerned institutes was also informed about the aim and objective of the study and they were assured their views and experiences including their names will never be leak-out as they were sharing important information regarding their official matter.

Thereafter, parents and family members were informed about the aim and objective of the study. An *Urdu* translated version of informed consent form was provided to them, which was also explained to them, thereafter, they were also assured

about confidentiality of their names and personal information they share about their personal life.

Moreover, permission for audio recording was taken from both parents and officials during In-depth Interviews and Focus Group Discussions. Similarly, pictures of the children with ID from both the official institutions and parents were taken, and pictures of the children as well as the equipment and other facilities available at the target institutions were captured for recognizing case to case stories and institutions.

Summary

The research was carried out on effects of child with intellectual disability on families in Khyber Pakhtunkhwa, Pakistan. It covered families initially in two districts, namely; *Peshawar* and *Haripur* while in the second part, the officials of the institutes were covered from four districts, namely, *Peshawar, Nowshehra, Mardan* and *Haripur* to know their roles in mitigation of the parents' miseries. In order to address the research objectives, it covered those institutes where the Centre for children with ID existed.

Hence, to investigate the effects of such children on families, parents were selected who had such children. As the issue of the effects of ID on families is related to the views, perceptions, experiences, problems of parents, therefore, a suitable technique i.e. Interpretative-Phenomenological approach was adopted to explore effects and roles in a holistic way. Keeping in view the nature of the issue, suitable data collection tools, such as participant observation and interview were employed. They were used with parents, mothers, fathers and other close family members and the special education centre staff who involved with such children and their parents.

Every question was thoroughly checked in the interview guide. Data collection was started when it was confirmed that questions in the interview guide are appropriate. Thereafter, an extra care was taken in transcription, analysis and discussion. Throughout

the research, ethical considerations were strictly followed by keeping their identity in secret, so that respondents' respect and dignity could be ensured.

CHAPTER 05 PARENTS' DISCOURSES ON EFFECTS OF INTELLECTUAL DISABILITYOF CHILDERN ON THE FAMILY

The previous chapter explained the methodological steps employed for carrying out this study while the current chapter presents the views of parents and my field observations regarding the effects of children with ID on families. Parents' discourses, together with field observation, provide detailed account of how children's ID affects the social, economic, and psychological aspects of families. Parents were selected from different socio-economic backgrounds for the purpose of getting broad perspectives of such effects. These diverse discourses in key themes have been organized, presented, and debated in a serious academic tone. In other words, such presentation provides a detailed account of how parents and family members spell out the effects of such children on their families.

In order to ensure a meaningful presentation, this chapter is divided into three parts. Part I delineates the social effects on the family caused by the negative attitudes associated with children with ID which results in social exclusion for mothers, migration for families, disturbed spousal relationship, extra fatigue for working mothers of such children, taunting and sarcastic remarks within family and among relatives owing the ID of their children. Part II describes economic effects such as increase in family expenditure which further affects the education of normal children and Part III explains the psychological effects of ID on family such as denial, guilt feeling, stress, depression, fear and their feeling of insecurity about the future of their children.

Part: I

5.1. Social Effects of Child's Intellectual Disability (ID) on the Family

As far the social effects on the family are concerned, these were observed and recorded during interaction with respondents both within the special education schools and their communities and families to obtain their genuine and authentic responses.

The different ways in which the parents and family members were affected by the indifferent attitude associated with such children are described below.

5.1.1 Social Exclusion of Parents/Family Members due to the Presence of Child with ID

Social exclusion among mothers as primary caregivers was found in the presence of a child with ID. Social exclusion means helplessness of person to participate in social activities such as work, polling, family-gatherings, and other routine activities (see Burchardt *et. al.*, 2002), he parents of such children in particular and family members in general were of the view that due to their intensive involvement in taking care of their disable children, they were unable to participate in events/ceremonies such as death or marriage even among their close relations or neighbours. Their movement was too restricted as they had to endure dual responsibilities of such children in particular and normal children in general. A mother in this regard stated her story of social exclusion in an individual interview in Peshawar as:

> "Previously, I led a very happy life: I participated in family events actively and used to attend happy occasions like marriage ceremonies. But after the birth of my two children with ID, my life has totally changed. Now, I do not participate in ceremonial activities of my family due to my fulltime involvement with my children. Similarly, my husband used to go to gym and meet frequently with friends. Now, he thinks all the time about the treatment and rehabilitation of the children. After office, he spends most of the time at home helping me in taking care of the children."

Social exclusion was not only found in this study but has also been recognized by Walters (1978) that parents who were exclusively busy in looking after their disable children were unable to participate in social and recreational activities.

The same was endorsed by mothers in a Focus Group Discussion (FGD) in Peshawar as:

> "We cannot participate in most of the ceremonies due to the look after of our children. In case of unavoidable situations, we attend but for a very short time, however, we remain extremely worried about our children at home".

On the other hand, the extreme burden in taking care of children with ID at the home needs help of others. It was found that some parents were able to participate in social activities of their community due to family support in child care and other household activities whether in form of hired helpers or relatives in the of joint family system. Grandparents and close relatives can extend emotional and social to the parents who have such children. With such support, the mothers were quite relax in extending support and primary care to their children which was reflected by mothers in different interviews, such as:

A mother in this regard reported in an Individual Interview in *Haripur*:

> "My sister-in-law and other relatives look after my child during my job timing and, hence, I am somewhat able to participate in community events".

A father narrated almost the same in an Individual Interview in Haripur:

> "My wife (mother of the disable child) receives support in child care of both normal and disable children at home as my sister-in-law looks after them. As a result, my wife is able to participate in community events."

Although social exclusion is a problem for all families having children with ID, its intensity is greatly determined by the particular structure of the family, i.e., nuclear and joint family structure. It was found in this study that the effects of bearing disable children were closely related to family structure. In a joint family structure, the adverse

effects are minimized due to family support; however, in a nuclear family, such effects are borne by the parents only. This has been explained as follows.

5.1.1.1 Social Exclusion and Nuclear Family Structure

Most of the respondents including mothers, fathers, and family members explained that since the number of members in nuclear family was comparatively lesser, therefore, the problem of social exclusion for such parents was high, i.e., their participation in social events, was too rare. Such parents were observed mostly complaining that their regular involvement with the disable children left them unable to continue regular participation in communal celebrations which they could do before. They realized the complaints of their relatives and neighbours of their failure to participate in such events; however, they were helpless because there was nobody in their families to take care of such children. A mother, realizing the complaints in this regard, lamented that

> "Owing to the extra care of my disable child, I am socially handicapped and cannot attend community events like marriage, death and other necessary events. I have to give time to my other normal children as well".

Almost the same explanation was given by a mother in a FGD in *Haripur* that:

> "A single intellectually disable child requires care equivalent to that of four children, as he/she faces difficulty in wearing clothes, eating and mobility due to which such children stay at home for most of the time. As a result, the mother is also required to stay with her child. Consequently, her full-time involvement with her child creates social complaints for her from the relatives and community members for not showing presence in social events".

Jamison (1965) in a study conducted in India and Pakistan has also found the same. In addition to this he has reported that it was too difficult for the mother of a disable child to cater all the needs and requirements of the disable child. He found that it was almost impossible for such a mother to endure alone the continuous burden of care of a disable child besides other domestic duties.

5.1.1.2. Joint Family and Social Inclusion

Unlike the nuclear family in which parents are exclusively responsible for taking care of their disable children, parents belonging to joint family received support of other family members in taking care of these special children and, hence, had spare time and opportunity to participate in social activities. They were supported both socially and financially by the family members such as grand-parents, sister-in-law, brother-in-law etc. in properly meeting the needs of such children. Such extra help from in-laws and other family members relieved the mother from some responsibilities and enabled her to give time not only to socialize but also enjoy recreational activities. This relived her emotional and physical stress strengthening her to shoulder her responsibilities more effectively.

For example, a mother belonging to joint family narrated her story in an Individual Interview in Peshawar as:

> "I give full time to the care of my special child. It is possible due to the support of my sister and mother-in-law. During my involvement with my child, they take care of other household activities and provide me time to look after my disable as well as normal children after coming from school. Moreover, I have never missed any social event of the community due to the family support".

The same was almost endorsed by all members in an FGD in Haripur:

> "It is very difficult for a mother to look after her disable as well as normal children and manage other household activities. The fact that we are sitting here today is due to the support of our family members. If we did not have their support, it would not be possible to participate in this discussion. Furthermore, in joint family system, workload is divided among the other family members which provides a breathing space to the mother to look after her disable child. Moreover, participation in community activities is also supported in joint families".

In addition to the opinion of parents expressed in the interviews, it was practically observed in all cases that the parents in joint family did not feel much pressure due to the presence of other family members in helping the disable children. They felt relaxed as compared to parents in nuclear families and held that "joint family

is a blessing, though its benefits are seldom realized by contemporary women". Furthermore, some parents' preferred joint family system in such situation due to financial, emotional, and social support to the otherwise abandoned disable children.

5.1.1.3. Cost Sharing

Besides social exclusion as an adverse effect, the special needs of children with ID[2] caused extra financial burden on parents. It was found in this study that joint family structure minimized financial burden on parents due to the pooling system of finances by all earning family members. As a result, parents faced no problem(s) in meeting the extra and special needs of their disable and normal children. On the other hand, parents belonging to nuclear family were extremely worried due to the extra expenditures on special needs of such children. They complained that their income was quite little as compared to the expenditures. The same experience of financial support in joint family was shared by a paternal uncle of child with ID in an Individual Interview in *Haripur* as:

> "The child lives with us in joint family, where he receives special care without any financial constraints. We have common pool system of income and expenditure due to which none of the family member feels over-burdened."

5.1.2. Social Support to Abandoned Children with Intellectual Disability

Besides social support and cost benefit to the family members, joint family was found as 'shelter home' for such children who were left-over by their parents after birth due to family breakup and separation. Moreover, it was also found that a mother who was unable to provide primary care to her children with disability handed over her disable child to other family members[3].

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[2]Children with ID suffer from numerous and different problems the intensity of which is greater as compared to normal children. Their needs/problems required enough resources which could not be easily met with meagre resources.

[3]The state of abandoned ID children is another important research area for the future researcher highlighted by this study.

It was observed in the study that members of the joint family showed no discrimination between disable and normal children. On the other hand, it was shared by parents during group and individual interviews that the lack of family support exposed such children to multiple abuses in society like abduction, child beggary etc. The story of an abandoned child was narrated by an uncle during his visit to the Institute for physiotherapy of the child with ID in Peshawar these terms:

> "This child with ID lives with his aunt and she treats him like her own child. His mother was unable to extend primary care to him due the burden of other 5 normal children and resultantly handed him over to her sister".

Another experience of children with ID was shared by a paternal uncle of a child who said that:

> "Just after the birth of the child with ID, his parents got separated. Hereafter, it was a challenge for the family as to who would look after him. Hence, his paternal uncles accepted the child as a family member. His mother abandoned the child for two reasons: she was unable to give extra time to him due to her job; and she considered him as an obstacle in the way of her second marriage".

From the above discussion, it can be concluded that family support to children with ID and their parents, especially to mothers is extremely necessary. Family support here means support in giving primary care like cleanliness, eating, toilet needs, and mobility of these children in addition to other normal siblings. Moreover, the study revealed that there was no institutional care and protection for such children who were abandoned by parents due to separation or family breakdown. In this extreme situation of indifference, such children are normally misplaced and found as 'missing children' in different newspapers. Such missing children are exposed to various inhuman abuses by criminal gangs who use them for begging, selling their organs of body like kidneys and may abuse them for sexually. A detailed discussion of this aspect of the lives of children with ID requires a detailed examination and is a potential area for future research studies.

5.2. Family Disorganization Due to Role Conflict and Lack of Social Support after the Birth of Child with ID:

A family is considered a primary social institution which provides primary care to the children and other vulnerable groups like aged and sick family members across the world. Family remains intact and works effectively in cooperation. In societies where family institution is weak, the state caters the needs of such individuals. Caring and looking after children with ID is a highly demanding job for parents and especially for mothers. Besides special needs, the severity/multiplicity of disabilities and age of children put un-ending burden on the parents. In such circumstances, both of the parents need financial support to afford their health, nutritional needs, and training. Such financial supports facilitate expenses for day care, special education schools, and various therapies for children with ID. These financial burdens keeps the father in mental strain when he is not unable to manage the required financial needs.

On the other hand, the mother is expected to perform multiple household roles that range from primary care of children, aged members, cooking, cleanliness, washing clothes to job in case of a working mother. This results in multiple social and psychological complications. Consequently, the relationship of husband and wife is normally at stake when these expectations are not met which results in discord and conflict in the family life. It was found in this study that marital breakdown stems largely from the fact that high expectation of domestic chores are associated with woman as a mother. Lack of cooperation and role conflict is more likely to put an end to family relationship (Haralambos, and Halborn, 2013: 362).

This study also reveals that parents experience disturbed relationship due to the birth of such children. In such situations, such children are neglected either by both or one parent. However, such cases were mostly observed in District *Haripur* which has different cultural features as compared to District Peshawar. There is a common

stereotype among the people of the province that the people of *Haripur* are different in terms of linguistic features and other practices and mostly resemble the people of *Punjab*. Compared to *Peshawar*, women in *Haripur* are more empowered and have fewer restrictions on their free mobility and social interaction with male members of society. Furthermore, the family structure in *Haripur* is mostly nuclear. These aspects of the district might play a role in why families in Haripur are more prone to breakdown in case they have a child with ID as compared to the rest of the areas in Khyber Pakhtunkhwa. Such information was gathered through in-depth interviews and informal discussions with family members. The staff of the special education schools who belongs to the same localities and areas also mentioned the higher prevalence ratio of divorces and family breakdown in Haripur. For instance, a teacher introduced a child with ID who could recite the ninety nine names of Allah in spite of his intellectual limitation. The teacher narrated in a sympathetic tone that the parents unluckily got separated due to the birth of the child. When the teacher was asked about further details, he stated that:

> "I know the family of the child whose parents got separated since long. They lived in nuclear family structure and both were doing full-time jobs. Owing to extra care of the child, his mother was unable to extend care to him. It affected the relation of the spouses that ended in divorce. Currently, he lives with his grandparents where he lives a happy life; however, they cannot extend care to him like his own mother".

Such family disorganization is the result of role conflict which adversely affects the spousal relationship and also pushes these children into destitution and isolation as there are no welfare homes for such children in the province. The only welfare home or protection is the joint family structure in this society which is considered as the vital social welfare institution in province. In an interview in Haripur, a paternal uncle of a deserted child with ID who had adopted him as his son expressed similar concerns:

> "The left over child lives with me and considers me as his father. His parents got separated after the birth of the child with ID and since then the child lives with me. His mother dwells in Karachi while his father is at Saudi Arabia. My sister extends care to him; however, she is getting married in near future and thereafter his grandmother will look after him".

Besides role conflict, divorce and separation of spouses also result from disrespect and verbal abuses and blaming each other for the defects of the child. Such defect of the child is normally associated with the actions or weakness of mother/wife as she is the weaker segment in Pakistani society due to lack of education and economic empowerment of the female family members. The mother of a child with ID narrated her story during an Individual Interview in Peshawar. She stated her experiences in extreme depression:

> "My husband is a daily wager; he is also addicted to drugs. The child needs extra care in terms of medication and nutrition but he cannot afford it. He blames me for disability of the child and beats me. This situation has really made me depressed and annoyed, however, I am helpless to do anything".

Thus, it reflects that family dis-organization is an evident effect of the birth of the child with ID which is associated with parental failure for fulfilling their special needs. In the absence of such support and cooperation, additional social, economic, and psychological burden falls on the spouses that causes familial disorientation that leads to disorganization.

5.3. Family-Work Conflict among Mothers of Children with ID

Besides social exclusion and family dis-organization, the birth of a child with ID causes family –work conflict for the mother in the family. Family-Work-conflict is most commonly defined as "a form of inter-role conflict in which the role pressures from work and family domains are mutually incompatible in some respect" (Greenhaus & Beutell, 1985:77). During field work of this research study it was observed that men are engaged in economic activities while a small number of women are engaged in paid

work. However, the involvement of women in paid work is slightly greater in district Haripur as compared to Peshawar. Moreover, it was also observed during the field work that women as mothers are more vulnerable to social, psychological, and medical adversaries due to full-time involvement with their disable and non-disable children. They are expected to extend more primary care as compared to fathers, though their contribution is not acknowledged due to patriarchal nature of the society. The husband or wife, typically the latter, may have to give up a job to stay at home with the child (Drew, 2000:331). Such affects are more unpleasant for working mothers belonging to nuclear families due to lack of social support. Resultantly, she has to strike balance in work as well as in household activities which is practically difficult for her and create further complexities in her life. She faces family-work conflict and undergoes continuous stress which causes psycho-somatic problems for her like depression, diabetes, and other illnesses. These children of working parents are supported by institutional care in the form of day care centres and special education schools in developed societies; however, such facilities are almost non-existent in Pakistan and only the family serves as a social welfare institution for most of the disable children.

In this regard, working parents belonging to nuclear families share their agonies of role-conflicts. On the other hand, the working mothers who live in joint families feel relatively relaxed due to the support of their in-laws during work which protects them from social, emotional, and economic breakdown to a greater extent. The mothers and family members narrated their stories of agonies both in Peshawar and Haripur. For instance, a working mother in Peshawar reflected upon her own agonies of family-work-conflicts in the following manner:

> "I remain continuously in stress due to the multiple roles I have to perform both within as well as outside the four-wall. I need two hours for feeding my child with ID, I am a working woman as well as have to give time to my other normal

children. Besides this, I give time to household activities. This extra effort has made me sick with high blood pressure (FGD with mothers in Peshawar)".

Almost all the working mothers belonging to nuclear families experience and articulate such distresses irrespective of rural and urban areas. For instance, a mother voiced the same feelings of conflicting situation during an interview

> "Initially, I was doing a private job, but after the birth of my child with ID, it was extremely difficult for me to make balance between work and household activities. Hence, I have given up that job for the sake of my daughter. But, I have restarted my job after admitting her in the Centre for disable children. However, I am extremely worried now owing to the suspension of the school's transport facilities due to installation of barrier on the road for security reason in my area" (Individual Interview with mother at Haripur)."

This research also highlighted that women mostly give up their jobs for the sake of primary care of the children and other family chores. However, one family had different a story to communicate in this case; instead of wife, the husband gave up his job to extend support to his wife and child with ID. During family visit, the researcher found that the wife was doing a high ranked Government job while the husband was doing job at a private organization in Islamabad. However, due to his absence during stay in Islamabad, his child and wife faced problems as they had a nuclear family and there was no other family member to support them. He had to make a choice. This is how he shared his feelings during an Individual Interview in *Peshawar*:

> "I am still missing my colleagues. I was doing job in a well-reputed organization (NCHD) as finance manager but my wife was unable to take care of the child in my absence. Although she admitted her in the Centre for Physically and Mentally Retarded Children at *Bashir Abad* where she also worked as the Head of the institute, even then, it was difficult to manage the home. Finally, I gave up my job. Now, I remain in stress which makes us (my wife & me) quarrel most of the time."

Hence, it can be said that working parents in general and working mothers in particular face family-work conflict due to extra involvement with these children at home and a job that require their full participation. As a result managing both activities

effectively becomes impossible. Owing to such conflicts, they were extremely overloaded and faced social exclusion (see social exclusion section 4.2.1), and other psychological and physical disorder. However, working parents living in joint family structure were confronted with less social, emotional, and psychological problems.

5.4. Family Displacement for the Sake of Treatment and Rehabilitation of Children with ID

Besides social and psychological effects on parents, it was also observed that the presence of children with ID also results in the displacement of families due to lack of treatment and rehabilitation facilities for children with ID in the province.

The term displacement refers to a social phenomenon of shifting of an individual or groups without their free well. It is a forced movement of people from their vicinity or social network and work-related activities for protection, survival or better social life (UNESCO, nd). It is a form of social change caused by a number of social, psychological and political factors (UNESCO, nd).

The birth of the child with ID is a shocking news for parents as it is a complex problem which needs early detection and therapies for social integration in the society. Moreover, in case of severity in disability like autism and cerebral palsy, the child needs extra care and social training for physical as well as intellectual improvement. Such disability is intensified when the child has difficulty in speech, hearing, locomotive limitation, and eye sight problems which normally require variety of therapies, trainings, and treatments in early life.

Besides parental and family support, institutional support and care is also inevitable for such children to integrate in society. However, it was observed during field visits of this study that there were no such institute or special education schools/centres equipped with the modern technology for therapies and no

trained/professional staff who could provide primary health care to these children. Moreover, parental care is closely associated with awareness and knowledge of disability of the child, while institutional care is associated with the availability of trained teachers/therapists and modern equipment for social training of such children. In case of non-availability of such facilities, the growth of such children might determinate.

In addition to the demanding nature of ID, the psychological agonies of the parents are intensified by the lack of required facilities in the special education centres. Most importantly, those parents who are more determined about the future and social integration of their children are more mindful about the selection of such institutes. Due to non-availability of such facilities, they opt displacement for the sake of rehabilitation of their children. It was observed during this study that some families settled in the capital of the country i.e., Islamabad, due to the easier access to such institutions which could minimize the problems of their children. Similarly, there was another family who shared with the researcher that they were planning to go to Australia for the sake of their children's recovery.

However, the nature of displacements also depends upon the financial condition of the parents. Those parents who reside in urbanized communities with high economic and educational background were significantly inclined towards such mobility. On the other hand, parents who had low finances with residence in rural community had low tendencies of displacement. For instance, a family settled in Peshawar who had two children with ID shifted to Islamabad where they admitted their children in a private institute. When they were approached and contacted by the researcher, they asserted that they were not willing for such displacement as they were enjoying a good life in joint family and had the support of all family members. However, they took that decision for the sake of their children's future. A family who had recently shifted to Islamabad was

approached and contacted through the office of the Special Education Centre Hayatabad Peshawar. The mother related her experiences in an extreme emotional tone during an Individual Interview in Peshawar:

> "We shifted to Islamabad where we admitted our two children in an Institute named Autistic Resource Centre (ARC). It was a very difficult decision to leave joint family as there was full support of family in care, finances and household management. However, after shifting, we are facing problems in social and financial adjustment due to the nuclear setup in Islamabad".

As far as displacement of families is concerned, they were not willing for it as they might lose family and financial support, but still they had taken that tough decision for the future of their children. The parents shared that they had observed improvements in the intellectual and social skills of their children which they considered a compensation for their sacrifices. A mother, who was approached during their family visit to Peshawar after shifting to Islamabad to learn about the effects of ID and progress in new centres, shared her experiences thus

> "We recently shifted to Islamabad and admitted our children there in a special education school. After admission, we have seen improvement in the social skills of our children. Initially, they were unable to understand and respond but now they can. Though, we have admitted them very late (i.e., at the age of 7 years and 9 years), however, they are improving gradually. If they were admitted somewhere in Peshawar, they might have shown no improvement (Interview with a mother in Peshawar)".

Even the official of the special education and social welfare institution were not satisfied from the out of these institutions, for example, an administrative head of the same centres who was also a mother of child with ID stated that will admit her child in private institute located at Islamabad. The main reason behind this displacement could be the poor state of services available for children with ID in Khyber Pakhtunkhwa. She said:

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> "She [her daughter] needs speech therapy and physiotherapy. We do not have such facilities here in the institute, and thus, I intend to shift to Islamabad for the sake of my child. I have personally raised voice for these facilities at every

> forum but the government is not interested to provide such facilities. We will shift to Islamabad soon after my retirement due to availability of very advanced and equipped institutes in Islamabad."

Other parents were willing to shift their children to Islamabad for better care, however they were unable to travel due to their permanent employment in the local area.

Hence, it was observed in this study that almost all the parents were serious about the full time recovery of their children and for the same purpose they opted for displacement. The reason of this displacement was the lack of required facilities in the institutes for full recovery of their children in the local area.

5.5. Verbal and Emotional Abuse of Parents in their Children with ID

Besides social exclusion, family disorganization, displacement of parents and work-family conflict as discussed above, parents in general and mothers in particular experience interpersonal effects as well. Such effects were in the form of verbal and emotional abuse of parents within and outside the family. "Verbal abuse is conceptualized as the use of language to hurt someone, whether it is with conscious or unconscious intent which is also called as emotional abuse" (Wedman, 2010). Similarly, verbal abuse is different from the emotional abuse as it "refers to any nonphysical behaviour that is used to control, intimidate, subjugate, demean, punish, or isolate another person through the use of degradation, humiliation, or fear" (Karakurt & Silver, 2013).

Parents experience an emotional setback after the birth of child with some deficiency. In addition to the agonies of the child, they face multifaceted problems of social stigma and taunt as well. However, the prevalence of stigma and taunt were observed differently in families with different socio-economic status in Khyber

Pakhtunkhwa. For instance, it was observed that parents who belonged to rural areas with less education were more prone to such abuses as compared to educated families.

Moreover, Khyber Pakhtunkhwa has a code of life called *Pakhtunwali*[4]. Under this custom, taunt or *paighore* (*Pushto* words for taunt) has adverse consequences due to which people normally avoid such actions which may cause taunt in a society. However, the birth of the child with ID is an unexpected incidence in their life; therefore, parents start hiding this. Such fear among the parents affect rehabilitation and improvement of their children as well. The reasons for such behaviours are illiteracy due to which they have no awareness about the cause and treatment of such problems. They associate the occurrences of ID with deeds of parents and influence of ghosts or supernatural entities.

A social case worker at the Institutes for such children was sharing his experiences regarding the attitude of Pashtuns about ID during an Interview in Peshawar that:

> "In Pakhtun society, ID among children is considered a divine revenge for the bad actions committed by their parents. As a result they do not accept/disclose the occurrence of such disability among their children. However, if they accept it, then they associate it either with the influence of evil spirits or 'evil eyes'. Besides that, they feel guilty for the birth of such children as they think it as a revenge for their deeds. Due to this negative attitude, they discriminate such children from the normal children in terms of education and health facilities. They prefer traditional healings over professional, medical or social therapies and treatments which further intensify the current state of affairs".

Besides superstitious perception of such disability, mothers are blamed and held responsible for the child's disability, even if the history of such disability is found in the fathers' family.

In this study, most of the parents were found seriously affected by the taunts for ID of their children. Parents shared that family members associated ID of their children

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[4]*Pakhtunwali* is a traditional lifestyle of the Pakhtun people which are normally characterized by honour (self-respect), *malmasthia* (hospitality), *badal* (revenge) and *nanawathi* (reconciliation) and is strongly associated with *paighore* (taunt). Pakhtun can go to any extent for restoring honour and avoiding taunting

with their deeds and actions, a moral stigma from which there is no escape. Similarly, mothers shared that they were jeered by their in-laws during domestic affairs which had caused emotional trauma for them. Such emotional abuse mostly occurs inside the family. This further intensifies the mother's emotional strain who feels helpless regarding the disability of her child.

Experiencing the same emotional abuse, a mother of such children started weeping during FGD in Peshawar and narrated her story with extreme sorrow:

> "My in-laws are usually taunting me for the disability of my child. They say that disability of my child is the result of my wrong doings".

It was also observed in this study that the practice of verbal and emotional abuse is higher in rural families where the ratio of education is low. It was shared by almost all parents belonging to rural areas that ID of their children was associated with their wrong doings. As a result, people in such areas avoid making matrimonial relations with those families due to the fear of having the same disability in their offspring. As a result, parents usually hide the disability of their children, especially of female child in their early age.

Most of the parents categorically stated that people in the rural areas named such children as *layewanee (Pushto* word mean 'Mad') or *chilaa* (*Urdu* word mean 'Mad'). Sharing the same issues during interviews and informal discussion with parents and family members, an uncle of a child shared his experiences of negative remarks in an Individual Interview in *Haripur*:

> "People's attitude in my locality is not good with my nephew having ID. They treat him as a source of entertainment and enjoyment. They cut remarks at him".

The same attitude of people about intellectual disability was shared by a father with extreme disappointment that people never treated him as a human being; rather

they considered him as some alien creature. They cut mocking remarks at his son. The same experience was shared by one such uncle of the child during an Individual Interview in Haripur:

> "Whenever my son goes out of home, people in the streets tease him by passing remarks. They enjoy this situation. I being a parent am highly irritated with such negative attitude and remarks of people; however, nothing can be done".

As evident from the interviews verbal and emotional abuses were significantly observed during the study. Moreover, due to lack of awareness among the masses, the collective attitude of the society is rather frustrating and hurting for the families and children with ID.

5.6. Parents discourses: Misconception among Parents about the Causes and Treatment of ID of their Child

Intellectual Disability carries evident effects on the family due to negative societal attitudes as discussed earlier in this chapter. There are certain myths and superstitions associated with the causes and treatment of ID in society.

In line with superstitions and misconceptions of parents regarding causes and treatment of ID, their responses are dissected into two categories. In the first part, parental discourses regarding causes of ID are discussed, while in the second part their views regarding treatment have been explained.

5.6.1. Parent's discourses about the Causes of ID of their Children

Intellectual disability is normally associated with the influence of devils or divine punishment. In this study, it was observed that parents who were not highly educated and affiliated with religion, attributed the causes of intellectual disability of their child to magic and its treatments through spiritual healing.

To elaborate the parental stance, detail of interviews with parents, and family members are hereby presented. A mother during an Individual Interview in Peshawar shared her views and perceptions regarding the causes of ID in her child,

> "After forty days of the birth of my child, I took the bath[5]; then, I visited a nearby village to attend a marriage ceremony during extremely cold weather. After attending a ceremony, when I was coming back at around 12 pm, I came across an area which was famous for *Jin and peeryan* (jinn or ghosts). Soon after reaching home, my child got reddish. We immediately wrapped the child in warm clothes, however, since then he developed ID. In this regard, people in my village say that it is due to the influence of "*Ghayeeb alam", peeryaan (unseen creature like spirits)*. Hereafter, we took him to *kaka saib*[6] where holy salt was taken from the shrine and brushed on the body of the child".

In this case, a mother who belonged to a rural area of Peshawar was convinced that the condition of the child was caused by the influence of ghosts rather than any physiological defect. In such situations, parents prefer spiritual healing rather than medical treatment. However, after some time when they observe no improvement in their child, they approach doctors or mental health professionals. But the child's development suffers due to ignorance of the parents. For instance, a five year old child with ID was brought to the Centre for Physiotherapy in Peshawar for the 1st time. He was unable to sit or stand independently. Apart from this physical problem, he had developed hyper-active/aggressive behaviour due to little interaction with the external world. When the Physiotherapist who dealt with this case was asked about the child's condition, he intimated us with his expert opinion:

> "In such condition, the child needs physiotherapy in early stage of life for protecting muscular stiffness. Moreover, he needs social interaction and speech therapies to improve social skills. This child has physical problems due to the lack of mobility and physical therapies and has developed emotional problem as

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[5]"Bath" here refers to the shower taken after 40th day of birth of a child. In Pakistan, and particularly, among the rural and semi-urban areas, Muslims women believe that taking bath before the 40th day of the birth of the child entails numerous diseases. Therefore, it is a common practice among most of the people in such area that they take shower after the 40th day of the birth of the child. Furthermore, this 'bath' is considered as cleansing ceremony wherein the nearby people are invited for celebration as an event.

[6]*Kaka Saib* Shrine is famous shrine of a saint located in district *Nowshehra* of Khyber Pakhtunkhwa. People from various parts of the country visit it for spiritual healing of their mental health problems and certain other chronic diseases like cancer, diabetes, and skin diseases.

well due to long isolation. Now, he needs extensive physical and psychological therapies to overcome both problems".

Similarly, most of the parents during interviews agreed about the influence of '*Bad Nazar*', meaning 'evil-eye' in causing ID in their child. According to them, such evil-eye-effects are caused by jealous relatives. This view was observed during Focus Group Discussions (FGDs) both in Peshawar and Haripur. For instance, when mothers were asked about the role of 'evil-eyes', all mothers collectively showed agreement with this phenomenon:

> "The effect of *nazer* (evil eye) is *Haq* ('truth', which could not be denied). We strongly believe that evil-eyes of the people can cause ID in child".

Other than spiritual and mythical causes, family members have also associated marital difficulties and abuses as a cause of ID in their child. For instance, a sister of a child with ID shared her opinion about the cause of ID during an Individual Interview at Haripur:

> "My father used to beat my mother during pregnancy and kept her in traumatic condition due to which the child developed this disability after birth".

Besides spousal abuse, other traumatic incidences were also shared by the parents as a cause of ID. For instance, a father shared other causes of ID of his child,

> "My wife had been my sister-in-law. After the death of my brother in a road accident in 1986, I married her in 1998 after a gap of 13 years. Then, she gave birth to "Junaid" (name of his child with ID). I believe that the long gap in conception and emotional trauma has caused ID in this child. Once I read in a newspaper that women who get widowed are exposed to hysteria or "*meergee*" (the interviewee confused hysteria with Epilepsy (called *meergee* in *Pashto*). As she is suffering from the same disease, the baby got affected and developed ID".

Hence, superstitions regarding ID were observed with high prevalence among the participants of this study.

The same participant also explained other causes of ID and associated it with the lack of proper hygiene in their locality. According to him, the cause of ID of his child is also connected with the insanitary condition of his village. He explained that:

> "I live in an area named "*Sardar*"colony. A stream of contaminated water is passing nearby the colony which contains wastages from all over the city of Peshawar. The same water is used by the people through self-dug water pumps. As a result, one out of 20 children suffers from such disability. My son is one of the affectees of the same problem".

When the families were asked about the source or basis of their respective opinions, they shared that such discourses were constructed by elders in general and aged women in particular in community gatherings, based on their life long observations and experiences. For example, a participant from Peshawar while debating the causes of ID in his child said:

> "I think there are three reasons for the disability of my son. First, because my wife had passed through emotional setback due to the death of her first husband, she gave birth to a mentally retarded child after marrying me. This perception was constructed by aged women in my family and neighbourhood immediately after the birth of my son. They believe that when a woman passes under the funeral-cot of her husband, she will give birth to a defected child. The second reason is that once my wife underwent severe pain during her pregnancy after jumping over a small stream. Moreover, she had also fallen from ladder during pregnancy, which may be the other cause of this disability".

It is evident from the above discussion that parents and people in general associate ID of children with a number of superstitions and myths. These include unfortunate fate of parents and child, perceived penalty for parental sin in their life, "evil eye", social interaction of the mother with retarded person, passing through the shock of husband's death/observing his funeral during pregnancy etc.

In contrast to the un-educated and rural dwelling participants, those participants who were educated, and had access to various sources of information regarding ID perceived ID as a medical condition.

For example, an educated mother was curious to know more about the medical condition of her child. She got admission in M.A Special Education at *Allama Iqbal* Open University, Islamabad, with the intension to understand the nature and cause of ID of her child. She explained her feelings (in an Individual Interview in *Haripur*):

> "Initially, I was very confused and disturbed after the birth of my child with ID, as society associated baseless myths with such disability. However, I was curious about the actual causes of such disability. When my child grew up, I admitted him in special education school, and during this period, I took admission in M.A Special Education program. After studying two semesters, I came to know that such a condition can be prevented and can also be controlled by early detection through various therapies".

When a Social Case Worker was asked about the state of gender disparity in education of female children with ID, he shared his experiences during an Individual Interview in Peshawar:

> "Being a Social Case Worker, I have frequent interaction with the parents to record child's case history. More than 95 % parents have no awareness about the causes & nature of intellectual disability. They associate ID with superstition. As a result, they do not consult doctors or psychologists. Moreover, they hesitate to send their disable children to any special education school especially girls as they consider education useless for disable female child".

Hence, lack of awareness and education about the cause and treatment of ID is the root cause of misconception and superstitious behaviour about ID of their child.

5.6.2. Discourses about the Treatment of Children with ID

There misconceptions among people in general and parents in particular about the causes of ID in their children. Parents either believe that the child's condition is irrecoverable or take their children to shrines and other faith healers.

As far as the followers of such attitudes were concerned, it was found in this study that such mythical attitudes were more prevalent among less educated families who thought the disability of their child as the 'will of God'. In some cases, parents accepted their disable child as a 'Gift of God' or "Allah Wali". Consequently, they were

hesitant about medical treatment of their children as they considered it an interference with the divine will.

Most of the parents belonging to rural areas with low socio-economic background preferred spiritual and traditional healing and took their children to shrines of saints and chanted words of the Quran. According to them, this is the only effective solution for such problems. On the other side, parents with sound educational and financial background preferred medical treatment for their children.

It was found that people who believed in superstitions and faith healings were fully aware about the history, locations, and effectiveness of traditional healing and treatment places. A father narrated his experiences about such treatment in Haripur in these words:

> "When I came to know about the disability of my son, I took him to *peers* (saints) and shrines for treatment. For this purpose, I took him to *Sarainum khan* for duaa (prayers). It is a place which had been a part of the court of King Akbar (*Akbar badsha ki darbar*) where saints or *peers* dwelled. The same *sarai* (inn) still exists and spiritual people like saints live there. Thereafter, I took my son to *Datha Darbar Lahore* (a prominent shrine in Lahore, Punjab) for *duaa* (prayers). I even took my son continuously for seven days to *Baree sarkar ki darbar* (another prominent shrine) for treatment and recovery where he was given food of "*Langar*" (free food served at a shrine). Resultantly, I have found some improvements in the hearing ability of my child".

Moreover, religious/spiritual leaders of prominent mosques or *madaris* (religious seminaries) are considered as sources of healing in such cases. Reflecting on same belief regarding healing, a grandmother shared her experiences of treating her grand-son during an FGD in Peshawar:

> "When a doctor revealed the disability of my grandson, I immediately took my grandson to holy places for *maanat* (wish and prayer to Allah through saint). Even, I sent his shirt to a *madrasa* named as *Banuree Madrassa* (a famous religious teaching Institute in Karachi[7]) for spelling Holy words on his shirt. After some time when we contacted them, they shared that the child had recovered then; however, his mother has to recite *Sureh Fatheh* (a verse in the Holy Quran) 100 times after each prayer and spell upon him as they came to

[7] Karachi is the major city of Pakistan situated in Sindh. It is also the capital of Sindh province of Pakistan.

> know through *Istheekhara*[8] that the child is under the influence of "*Dewoo sayia*" (spirit or ghosts)".

Similarly, such superstitious belief system about treatments were not restricted to only one area of this research study, but were followed in the whole province in general and in rural areas in particular .

Besides taking the child to the shrine of a saint or a religious institution for blessings, other traditional practices were also found among the participants of the study. For instance, a mother who had brought her son with ID for physiotherapy to a hospital shared a unique mode of traditional treatment of her child during Individual Interview in *Peshawar:*

> "For early recovery of my son, elder females of my area advised me to expose him to seven different *thandoors (ovens)*[9] at neighbourhood for seven weeks on each Sunday. Therefore, I followed the same method and took my son to seven ovens and exposed him for ten minutes at each oven. Thereafter, I observed improvement in his physical movement".

Hence, there were misconceptions and myths about the causes and treatment of ID in the field area of this study. People considered ID as a complex problem about which there were many unscientific beliefs prevailing among families and parents. They considered it, a trial imposed by Allah, a condition caused by 'evil-eyes', or an influence of ghosts etc. People believed that such a condition was beyond human control, and considered the saints and shrines as the most effective places for their treatment. Moreover, people believed that although such children were not productive in society, they were a source of economic prosperity in this world and a source of salvation in hereafter as these children were a revelation of God's will.

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[8] *Istikhara* means to seek goodness from Allah. When people intend to do an important task, they turn towards*Istikhara* before the task. The one who does the *isthikhara* is as if they request Allah Almighty that, O the Knower of Unseen, guide me if this task is better for me or not. (Islamic Academy)
[9] *Tandoor* is both *Urdu* and *Pashtho* language word which means large clay-made-oven installed in one corner of the home for cooking breads.

On the other hand, those parents who were more educated and ambitious about the future of their children, were motivated to get accurate information about the nature and treatment of such disability and took them to suitable centres/institutes for rehabilitation and training.

Part: II

5.7. Economic Effects on Families with Intellectually Disable Child

The earlier sections of this chapter highlighted the social effects of a child with ID on the family such as social exclusion, family disorganization, family displacement, family-work conflict, verbal and emotional abuses of parents and the children with ID. This part explores the economic effects of children with ID on the family as they have special needs regarding transportation, support, nutrition, medication, education, and social training which require sound financial condition of the family. Parents with meagre resources face financial problems in dealing with ID.

5. 7.1. Extra Financial Burden Compelled Parents for Second Job and seeking Loan

Beside extra social support, such children required extra medication, extra treatment, special education, and transportation. Besides food and other extra needs of these children, they require extra medical care for physical and psychological strength. Children with ID who suffer from physical limitation need regular physiotherapies and exercise for their physical strengths. Besides intellectual limitation, these children are also suffering from physical weakness. As result, most of such children were suffering from chest and digestive problems, hence, they needed consistent medication and treatment such as MRI, which is a type of X-ray required for diagnosis of brain's function and diseases. Such processes need ample financial resources.

In addition to this, such children mostly required special transport facilities due to problems in mobility in schools or community. Hence, parents are required to make special arrangement of transport which again needs extra financial resources. For their education, such children need special education and social training which is not possible in normal schools. Therefore, special finances are needed for their admission in special education schools and training institutions.

Parents who were financially sound were not affected badly. However, those who had poor financial conditions faced serious financial problems. Family members, especially the father had to do extra jobs or get loans from various sources. Such situations were normally encountered by those parents who lived in nuclear families. A mother shared her feelings of financial agonies in the following words:

> "My husband took a loan from his department for the treatment and rehabilitation of our children, as it was very difficult for us to afford their treatment in a specialised institution."

In this regard, a father who was passing through the financial stress due to shortage of resources and the extra medical demands of his disable child reflected his views as follows:

> "The doctor has prescribed regular physiotherapy for three to four months for the physical improvement of the child. However, due to poverty, I cannot afford such treatment. We reside in a rented house (rent of Rs. 2500/- per month), but, my salary is Rs. 6000/- per month. It is difficult for me to bear the expenses of my family."

Families of such children faces extra problems in fulfilling their multiple social, psychological and medical needs. Such demands also exert extra financial burden on the such families. Consequently, the struggle for extra finances compelled parents to work extra hours in normal routine. However, families who were living in joint family structure were better able to bear the financial burden due to the support provided by other family members in a joint household.

For instance, the guardian of a child shared these views about the less financial burden due to a common and collective system of finances in joint families:

> "We have joint family, in which all members contribute their share which is kept by my father from which all the expenses including the care and education of my child with ID is borne. Consequently, we never felt financial burden".

On the other side, families which were poor and nuclear in structure faced serious financial challenges and were suffering from serious economic torments.

5.7.2. Effect on Normal Children

Beside multiple effects on parents and social functioning of families, normal or non-disable sibling also affected due to the presence of such children. Mostly poor families, where extra care and demand of such children, affect financial condition, as a result, normal sibling receive poor food, health and education facilities. It was also found that some parents had forced their normal children into child beggary and/or child labour to cater to the needs of their disable children. Reflecting on this situation, a member in a FDG in Peshawar narrated that:

> "We have seen such families of disable who are extremely poor. They use their children for begging in the streets to afford their family expenses".

Some families forced their normal children into child labour and beggary due to weak financial condition. Such extra steps affect personality and future of the normal children. Moreover, female siblings were affected more as compared to male siblings. The normal female sibling were mostly supporting her mother in taking care of the disable children, as result she has to give up her education.

5.7.3. Theological Beliefs Provide Support to Parents in Extra Expenditure

The parents were complaining of the financial agonies due to extra/special needs and problems of such children. However, those parents who were inclined towards

religion were relaxed due to expected reward in the eternal life and economic prosperity in this world. Parents were accepting these children as blessings of God. Though, most families were financially poor but even then they did not complain about the extra financial burden.

Moreover, they believed that before the birth of their child, they were facing financial limitations, however, after the birth, they had seen evident prosperity.

When the question of economic burden due to the birth of a child with ID was put to mothers during an FGD in Haripur, there was a split of opinion: those who had religion-oriented approach were very optimistic while those who were not associating ID of their children with religion were crying of financial problems.

> "We (family of the child) believe that such children are gift of Allah rather than a curse. Allah will reward those parents who take care and look after their children whole-heartedly. Of course, the birth of such children exert financial burden on the family, but Allah compensates it in other ways. Our husbands were facing financial constrains in business, but the birth of these children appeared as a source of prosperity. We have seen evident increase in our *rizaq* (earnings)".

Similarly, those parents who adhered to the Islamic teaching of charity and support for destitute expressed great satisfaction over spending on, and fulfilling the needs of their children. Furthermore, the concept of fear and reward after death has protected them from complaint. Islam holds people accountable to God for their deeds on earth (Macionous, 1993). It was also endorsed by Malinowski that religion reinforces social solidarity in dealing with a situation of emotional stress (Haralambos and Holborn, 2013).

This view was corroborated by a father during an Individual Interview in Haripur who apparently belonged to a poor family but was optimistic about the birth of his daughter with ID:

> "Whatever I have today is due to the birth of my daughter. I have a strong faith in Allah that He blessed me with economic prosperity and expanded my

livelihood after the birth of my daughter with ID. I have never faced financial constraints in providing her treatment and other care".

The same feelings of satisfaction were expressed by a father during an Individual Interview in Peshawar, who had two sons with ID.

> "Of course, it was a shocking news for the whole family that both our male children were afflicted with ID. But, we realized that they (sons) are given by Allah and we have accepted them as gift of Allah rather than a curse. These children may be a test from Allah for our patience and faith. *Alhamdulillah*, currently I am very happy with them. Allah has expanded my business and enhanced my financial sources. I believe that this prosperity is due to the birth of these children. I and my whole family love them".

On the other side, it was observed that those parents who were financially well-off and belonged to renowned political and social background, were seriously complaining of both emotional and financial burden due to the birth of such children. For examples, a group of mothers who belonged to well-off families were seriously complaining of financial burden during Focus Group Discussion (FGDs) in Peshawar:

> "The birth of our children with ID was not less than a social, psychical, and economic disaster. We felt extremely depressed as they have completely handicapped us socially and economically. We provide extra care in terms of food, social care and mobility. We spend full time with them which has made us socially isolated from our families. Similarly, we are taking them to doctors on regular basis; we have hired a servant for their pick and drop to special education schools".

Such agonies due to financial and social burdens were expressed in an emotional tone by a mother who belonged to a renowned political family during Individual Interview in Peshawar:

> "The birth of my daughter with ID has put an extra social and financial pressure on me and my family. I passed through emotional set-back and once I attempted suicide due to the social and emotional pressure".

The birth of such children caused socio-economic disaster for the parents and other family members in terms of social exclusion, family disorganization and financial burden which normally disturbed them. However, parents and families adhered to

religious injunctions of charity and support which provided them with strength and enabled them to bear the burdens with open hearts. They considered the care and look after of their children as a source of divine benediction and worldly prosperity. Hence, affiliation and adherence with the religion of Islam were found as a social capital which had protected them from social, emotional, and financial breakdown.

5.7.4. Gender Disparity in Expenditure

Besides religion, culture was observed as an important factor in determining resource mobilization for children with ID. Normally, sons are preferred over daughters in Pashtun society. It was found that female children with disabilities were more likely to be excluded from special education and mobility.

It has been noted through this study that there was no special education centre exclusively for girls with special needs, though they constitute a substantial segment of the disable population. It was further observed that enrolment of female children was very low in the centres. The low ratio of female children in the centres is also evident from the fact that only nine (16%) of parents of female children with ID had participated in the study. On the other side, forty nine (84 %) parents having male children participated in the study. When a staff member of the centre was asked about the fewer number of female children in the centre, he explained that parents preferred male children over female with ID for participation in special education.

Furthermore, it was also observed that parents were quick to drop out their female children from schools/centres when they reached the age of 10 or 12 due to cultural constraints of gender segregation.

It was noted in this study that the prevalent culture normally determined gender preference of special education, that is, who shall attend special education?. Generally, in Pashtun society a male child is given preference over a female child when it comes to

education in general and special education in particular. Parents invest in their male children with the intention that he will be earning for the family in future. Female child, on the other hand is perceived as non-productive economically for the family and is considered also a guest in the family as she will be ultimately married off. Therefore, parents prefer a male child over a female child. A grandmother shared her experiences during an Individual Interview in Peshawar and presented justification for the gender inequality:

> "Two of my grand-children suffered from such disability. One is male child while the other is female. As far as the education of the children is concerned, the family can afford their education, however, we decided to allow male child to attend special education school while female child was kept at home as she cannot protect herself from any abuses".

This study reveals that female children with disabilities were discriminated against due to their non-productive status in society. Such discrimination was not only restricted to family but was also observed at the level of special education institutions as well. For instance, a father was annoyed with the attitude of staff members of special education Centre for continuously insisting to take his female child home due to her menses problem. He narrated that:

> "We have dropped out our female child from the school with Down Syndrome as she was passing through menses problem. The teachers were complaining continuously and asked me to either solve her problem through operation or stop sending her to the school".

Hence, it was found that female children with ID were discriminated against on the basis of gender and disability. The prevalent culture was found as a license for such discrimination as a male child was considered a source of strength and earning in the future. Consequently, the participation of male children in the special education schools was higher as compared to female. Moreover, the staff members of the institutions were also discriminating between male and female children. There were no separate special

education schools for the female children in the province. As a result, parents took away female children after reaching the age of puberty.

Part: III

5.8. Psychological Effects of Child with Intellectual Disability

The previous part described social and economic effects of a child with ID on the family which develops in psychological problems like depression and stress. This part of the chapter explores and discusses the psychological and emotional problems of parents having children with ID.

A child with ID in the family requires special care and attention which poses restrictive time demands on the family members. Such daily extra demands exert psychological pressure on both family and parental functioning. In this study, parents indicated that they often felt socially isolated which led to hopelessness. It was reported by the parent that feelings of being down, depressed, or hopeless were prevalent in their life due to the condition of their child ID.

5.8.1. Emotional setback of parents on recognition of ID of their child

Besides other agonies, recognition of ID was shocking news for parents as they were not ready to accept their children with defect. Socio-cultural factor were responsible for the lack of acceptance (denial) as referred to earlier in Chapter Four of this thesis. As a result, the early recovery or control of ID of the child suffered a lot.

However, it was also found that parents in some cases were unable to recognize the mild ID due to lack of awareness as they were comparing the child's condition with the slowness the other family members demonstrated in their childhood. Consequently, they had been sent their ID children to the school for normal children where the school authority informed them about their unusual behaviour and weak performance. In some cases, initially the parents were blaming teachers and schools authority for their

inefficiency to teach them. It was shared by majority of the fathers during FGD that they were unable to recognize the disability of their child due to lack of awareness about the disability. However, they accepted it when the authorities of the normal school informed them about their unusual behaviour and weak performance. They shared the same experience during FGD in Haripur:

> "Initially, we considered our child normal as he was growing physically. As a result we admitted him in a normal education school. However, after passing sometime in the school, we took him out of the school and admitted him in special education school".

Similarly, some of the parents in the same FGD in Haripur shared their experiences of ID of their children:

> "Our child was not growing as compared to the other normal children. Hence, we approached to a child physician who advised us to admit the child in special education school as their mental growth was slower than normal children. Therefore, we admitted him there".

However, severe ID in children can easily be recognized after birth which are mostly associated with other symptoms like smaller or larger head, physical deformity etc. The effect of such disability is more shocking for the parents as it is revealed immediately after birth. In such condition, parents go through grief, shock, denial, and anger, and consider their troubles unmerited and afflicting (Hattersley, 1987).
The same traumatic feelings were expressed by a mother during an Individual Interview in Peshawar:

> "I cannot forget that moment when the doctors told me that the child has got disability. It was a shocking news for me and I suffered for many days and even attempted suicide."

Similarly, a grandmother was describing the difficulty in the recognition of ID of her child and first reaction thereafter during FGD in Peshawar:

> "The child was normal after birth; he was showing normal gestures like normal children. However, when he reached the age of two, he could not

develop then. We immediately took him to the doctor of brain ('*da demaghoo* doctor' means Psychiatrist) who started medication. However, he used to sleep for days after taking that medicine and when he would wake up he used to behave angrily and started crying. Then, we stopped that medicine, thereafter, he used to get peaceful. When he reached the age of about five years, we admitted him in the school of normal children but the school authority started complaining of his unusual behaviour. Thereafter, we took him to a psychologist who advised us to admit him in the school of disable children."

It was observed in the study that parents and family members were unable to recognize ID of their children at early stage due to lack of awareness about such disability. Some intentionally denied any disability in their children due to cultural and social stigmatization. However, in more severe cases, the doctors usually revealed to the parents immediately after birth about such disability. Such moments were extremely difficult for the parents and family. They reacted in the form of denial, guilt or blaming.

Similarly, other parents also admitted having had a problem in recognition of the disability of their children. For instance, a mother who was sharing her experience during FGD in Peshawar said:

> "After birth of the child, I was doubtful about the gestures and responses of my child. As he was slow in behaviour and was giving very slow responses. When he grown up, when I exposed the child to people in different family occasions, people reinforced that the child was not behaving in a normal way. Thereafter, we took him to a child specialist who revealed for the first time that the mental growth of the child will be slow as he was afflicted with mental retardation."

The difficulty in recognition of ID also affects the early detection of disability which further causes complication in rehabilitation. The experience of late recognition was shared by a mother during an Individual Interview in *Peshawar*:

> "We realized the disability of our child very late and the doctors advised him speech therapy. Because there were no facilities of speech therapies in Peshawar, we shifted him to Islamabad and admitted him in a Centre working for the treatment of such children. However, the doctors and psychologists told us that we had brought the child very late as was past the age of 7 years and at this stage it would be very difficult for them to effectively treat his disability".

Similarly, it was observed in this study that providing care and looking after such children exerts extra pressure on the parents. In such condition the children needed extra time and resources for caring. They needed special attention for nutrition, mobility, cleansing, and toilet requirement.

As the primary care of such children was extremely difficult job; as a result, mothers were observed as the most affected segment in society. Primary care-giving was observed as the primary responsibility of the mothers besides other household work. The same problem was reflected by mothers during different interviews in Peshawar and Haripur. For instance, a mother who shared her miseries with extreme emotional tone during in an Individual Interview in Peshawar said:

> "I was already overworked with household activities and primary care-giving responsibilities, however, after the birth of my child with mental retardation, I was much more over-loaded. My disable child needs continuous attentions and care during eating, bathing, mobility, and clothing. He cannot be left in isolation for a single moment. As a result of such hectic tasks, I have developed irritation and continuous headache. Even my sleeping routine is disturbed".

Furthermore, working parents who resided in nuclear structure, faced multifaceted psychological problems (also see Social Exclusion in this chapter on pp. 2-5). Such parents especially mothers faced serious stress due to role conflict.

The same feeling of depression and stress was shared by a mother during FGD in Peshawar with agreement with other members loudly and emphatically that the care of the child with ID and working status multiply stress of the mothers:

> "After the birth of my child, I remained continuously in stress due to multiple roles both within as well as outside the four- wall. I need 2 hours for feeding my child as he cannot eat and digest like normal children. Moreover, I am a working women as well. Hence, besides job, I give time to household activities. Consequently, such extra effort has made me a patient of high blood pressure".

Besides, job stress and extra care of such children, parents faced complaints of their normal children and in-laws of not giving them attention; as result it, annoyed the mothers.

The same complaints were shared by a mother during in an Individual Interview in Peshawar that,

> "Besides the care-giving burden, my normal children always accuse me of giving preference to the child with ID and ignoring them. Similarly, my in-laws and other close family members always complain for not paying visits and attention to them. Such complaints make me more depressed".

Hence, it is clear that it is difficult for the parent to recognize and accept the ID disability of their children on time. Late recognition has multiple reasons. Some parents were really unable to recognize the ID of their children due to the slow revelation of the disability which is called moderate ID. Early recognition of disability can minimize the intensity of such disability up to a great extent. Moreover, there were other types of ID such as autism in which the child did not show normal gesture or reaction to external responses. In such condition, it was found that parents recognized it but did not accept such disability due to the fear of stigma. Some types of ID which were recognized immediately after birth due to their evident symptoms. Such conditions also exerted extra emotional burden and shock for the parents as they expected a normal child.

The parents faced serious stress due to extra care and full time involvement care for a child with ID. Furthermore, parents who belonged to nuclear setup and had to work as well suffered from chronic stress due to multiple roles within family and outside the home. Similarly, they also faced complaints from the normal children as well in-laws for not paying attention to them.

5.8.2. Fear of Mislay of ID Children &Dishonour Family

Besides other psychological problems, parents expressed serious fear of mislay of their children with ID. Owing to limitations in memorizing their own places, ID children can go astray during play outside their home. Severely retarded children cannot easily remember the pathways of their home. They are more prone to getting lost in the streets. Mislay of an ID child can cause trouble for parents as they have to run around the community and announce through loudspeakers of different mosques. Besides this, parents usually lodge a missing report in the nearby police station and advertise in local and national newspapers that "a child with ID has been mislaid".

Furthermore, it was shared by parents that such children were usually kidnapped by criminal gangs who could use them for begging or selling their organs like kidneys so that they could provide extra care and protection to such children.

Moreover, the family also perceived a strong risk of causing a loss of family *izzat* (pride, honour, face) through some accident or unbecoming incident, especially where 'honor' is bound up with the sexual innocence of daughters. These prevalent fears had been shared by most of the parents.

It was found in the study that some of the parents had pasted a 'name and address' sticker on the back of the children or near the front pocket just to protect them from mislay in case they go outside.

For instance, the problem of mislay was shared by an uncle during in an Individual Interview in Haripur,

> "My child with ID is extremely hyper-active. He cannot sit in one place. Keeping in view his nature, we have installed interlock system in our doors just to avoid his mislay. In the past, he had gone missing on many occasions which were difficult moments for us. In order to avoid such incidence again, we have adopted preventive measures to avoid his mislay".

Besides mislay, parents were extremely worried for their female child with ID due to their femininity. As compared to male children a female child could not protect herself from sexual abuses. The same problems and fear was shared by a grandmother during FGD in Peshawar which was also supported by other mothers in Peshawar:

> "We are extremely worried for our female children with ID as they cannot protect themselves from abuses. They are growing up and it increases our worries".

The same problems was shared by a mother who emphatically stated her fear about her female child in Focus Group Discussion in Peshawar that,

> "As a mother, I am extremely worried for my daughter with ID. Boys can go outside and play with their age-mates but I cannot allow my daughter due to the fear of sexual exploitation. Similarly, I am worried about her future as she is growing and passing through different physical changes. I am worried about how she will help herself and protect herself".

To avoid such fear, sometimes parents/family members use some inhuman tactics. As it was reported by a Social Case Worker in the Centre for Child with Physical and Intellectual Disability in Peshawar, that once they visited a family for follow up of children, where they found an adult man chained to cot within the home. When they asked for the reason, the family said that it was due to the fear of mislay. The family had kept him for 20 years in such condition.

In short, it was found out that children with ID are a source of fear for parents as these children can easily go missing. Such children are unable to protect themselves from any abuse; therefore they can be misused for any criminal and inhuman purposes like begging and organ transplantation. In case child was female, parents were also feeling a continuous threat to their family honour because female children with ID could be sexually molested and abused. Such fears were increasing with the growth of such children.

5.8.3. Anxious about the Future of the Child

Besides other miseries, parents were concerned for the future of their children. Most of the parents had the pressing question that "what will be the condition of my/our son/daughter after my/our death?" In the presence of parents, children are normally protected and secured from all types abuses; however, they were uncertain about their future. Furthermore, there were no social welfare institutions for the care and welfare of such children. Thus, parents were fearful that without their support, their disable children would end up in the streets or would have to live a dependent and miserable. Owing to this fear, some of the parents had certain future plans for the support and protection of their children after their deaths, such as opening a small business or purchasing a piece of land in the name of the child which would protect them economically. However, most of the poor families sadly shared that they had nothing to offer for protecting the future of their disable children except prayers. They hoped that only Allah would keep them protected from various victimizations and abuses.

A father was sharing concerns for the future of his son with ID during an Individual Interview in Peshawar:

> "I wish that they shall get good education and can live independent life. However, I believe that they would live good life; Allah would protect them and provide them all the basic amenities. Their other siblings are very kind, they would hopefully support them. I am thinking of purchasing some land in the name of these children so that they will get benefit from it and would live their life".

Hence, parents and especially mother are extremely prone to various psychological and emotional problems like denial, fear, stress and depression caused by the ID of their children. Such psychological conditions are mostly caused by the societal pressure due to the nature of the disability. Such disability was normally associated with familial or parental defect and cause stigma to the parents and family. Resultantly, family and parents bore such children with continuous stress and depression.

Summary of the Chapter

This chapter presented the various effects caused by the birth of child with ID in the family. Part I of this chapter delineated the social effects on the family caused by children with ID. The effects varied from family to family and gender to gender. For instance, the effects of child with ID were much higher and adverse in nuclear families where parents especially mothers were adversely effected. The parents were facing various effects such as social exclusion, disturbed spousal relationship, extra fatigue especially for the working mothers residing in nuclear families. However, mothers living in joint families were mostly exempted from such social effects. They were facing taunting and sarcastic remarks within joint families from relatives.

Part II described economic effects such as enhancement in family expenditure which exerted financial pressure on the father who was normally the sole bread-earner. Moreover, such financial burden further affected the education of normal children.

Part III explained the psychological effects of ID on family such as denial, guilt feeling, stress, depression, fear and their feeling of insecurity about the future of their children.

CHAPTER 06 VIEWS OF THE OFFICIALS ABOUT THE EFFICACY OF FACILITIES EXTENDED BY GOVERNMENT TO MITIGATE THE SUFFERINGS OF THE FAMILIES

The previous chapter presented the views of parents about the social, economic and psychological effects of intellectual disability of children on the family, while this chapter presents in detail the views of officials of the Special Education Schools and Centers regarding their role in mitigating the sufferings of parents having intellectually disable children[10]. In order to develop a clear understanding of the whole issue, this chapter is divided into three parts. Part I explains the role of special education institutions in district *Peshawar* and *Haripur* in providing different social services to such children, while part II describes the role and efficiency of such services in child's development and mitigating sufferings of parents. The last part explains the problems faced by the officials in performing their role in mitigating the sufferings of parents. The purpose of presenting such an account is to provide the reader(s) a holistic and unambiguous picture of how such institutions performed in different places of the study areas.

Part 1

6.1. Views of the officials about their role in mitigating miseries of parents

This part, as referred above, provides a description of the views of officials such as social case workers, special education teachers, managers, physiotherapists,

[10]This chapter like the earlier chapters uses the word children for 'child or children with intellectually disability (ID). Using the word child or children for such disable children avoids repetition. However, it is worth-mentioning that whenever the writer refers to normal children it would be made completely clear by using 'normal' as a prefix or suffix.

vocational trainers, doctors, and psychologists regarding their role in the rehabilitation of children with ID and mitigating the sufferings of their parents. Such officials performed different activities/duties ranging from assessment of the nature and types of disability to the practical therapies of children in special education institutions. The extent to which such activities improved the situation of children with ID is described here.

6.2. Assessment of disability of the child and socio-economic conditions of the parents

Assessment is the core duty of the service providing staff. Moreover, it is also considered as an initial step towards rehabilitation of children with ID. Assessments are of two types: 'pre-admission assessment' is carried out before admission for considering child's suitability for registration in the centre/school while 'post-admission assessment' is normally carried out after admission for the purpose of child's suitability for a particular class or level of training. As far as pre-admission assessment is concerned, the officials of such centres considered such assessment as a thorough analysis of the child's disability and socio-economic conditions of the parents. Such assessment is initiated by a social case worker and finally accomplished by other professionals such as doctors and a team of special education teachers, audiologists, physiotherapists etc. during post-admission assessment. In this process, the age and type of disability of the child is also determined for admission purposes. According to the officials, the age of a child for admission is 4 ½ to 13 or 14 years while the type of disability, required for admission, is mild and moderate. However, children having severe type of intellectual disability are not considered for admission due to lack of available resources and staff required for dealing with such children. Justifying such criteria for admission, a special education

teacher, who was also involved in the assessment of child's disability, explained in individual interview that:

> "We do not admit children with severe intellectual disability because the institute lacks attendants or *Aayaas*[11] (female attendants) who are extremely necessary for helping children with severe disability in classroom situation (Interview with officials in District *Mardan*)".

However, it was observed that there were some institutions where children having ID were admitted and were made to set with children having other type of disability like hearing, speech or visual. Moreover, the age criterion was also not observed in some of the centres in district *Peshawar* and *Haripur* where children as well as adults were allowed to set in the same classroom. When this issue was discussed with Heads of the institutes in *Peshawar* and *Haripur*, they gave almost similar justification that they were convinced of 'theory of necessity' which meant they had to accommodate the need of the people. For example, the head of the Institute in *Haripur* explained:

> "There is no other institutes in the area to deal with such complicated disability, hence, I admit and allow them to set in the class room of children having both mental retardation as well as other disability like deafness and dumbness. Moreover children above 18 years are also allowed due to the extreme requests of the parents" Almost similar response was also provided by the head of the institute in Peshawar where a number of adults were seen admitted within the same class of children with ID and other disabilities".

Elaborating further upon the admission process and pre-admission assessment of children with intellectual disability, the Director of Special Education Complex, *Hayatabad Peshawar* expounded his rationale during in an Individual Interview:

> "We receive all types of Mentally Retarded Children, however, after assessment, we decided if we can accommodate the child or not. Besides the nature of disability, we also look into available space in class rooms as well as buses available for pick and drop".

Moreover, socio-economic conditions of the parents are also recorded during assessment process for determining the causes of disability and entitlements of the child

[11] *Apa* is a Urdu language word which is officially used for woman working as supporting staff in educational institution in Pakistan.

for different facilities like transportation and scholarships. Parents are supposed to produce medical certificate/ disability certificate reflecting mental disability of their children. Though, most of the parents lack such certificates, therefore, the social case worker usually diagnoses it by administering disability assessment performa. After registration, the social case worker develops and maintains a child's profile consisting of disability certificate, birth certificate, address, and parent's financial status etc.

After admission, the child undergoes further medical and psychological assessment for assessing child's suitability for social skill training or education. Thereafter, a thorough assessment is carried out by the team of experts and the child is referred to a specific class where his/her education and other trainings begin.

6.3. Social Skill Trainings Imparted to Children with ID

After pre and post assessment processes, the child undergoes further rehabilitative processes such as social skill trainings etc. Social skills enable children with ID to perform properly in a variety of social situations (such as work, school, and interpersonal relationships).

In special education centres, children with IDs are taught behavioral management skills, for instance, how to talk and speak by keeping an appropriate volume while conversing with others. They learn how to behave in different situations in society. However, the type and extent of such rehabilitative training is determined by the team of experts during post-admission assessment process.

So far as children with ID are concerned, the officials shared that they provide selective educational training, social skill training and vocational training. Selective training means training according to the IQ, type of disability and age of the child. For instance, children with mild intellectual disability or slow learner are taught reading and writing skills up to 5^{th} or 6^{th}grade. On the other hand, children with moderate disability

are provided with social skills training or daily living skills such as how to eat, drink, dress, behave in certain situations and use toilets appropriately. Elaborating the child's suitability for these training, a social case worker presented his view regarding types of social skill training during in an Individual Interview in *Peshawar:*

> "The services to the children with MR are provided according to the type of MR. As for children with moderate mental retardation[12] are concerned, we provide them social training for keeping themselves clean, do not wet their clothes, tie their laces, wear and change their dresses. They are also trained to cross the road, know their names and recognize their parents"

The social case worker further elaborated disability-wise services in detail during in an Individual interview in Peshawar:

> "Children with mild mental retardation are helped to learn alphabets and counting up to at least 15. They are taught to read and write simple words. They are further helped to increase vocabulary by relating their studies with things and activities of their daily life. Children with slow learning are provided with education which can go up to primary level. They are assisted to read and write simple words, differentiate colors, shape, and size and solve simple puzzles"

Explaining further the importance of social skills training, the Director of Special Education Complex, Hayatabad Peshawar shared his view in an Individual Interview:

> "Before admission, the parents said that their children had disturbed routine in the family. However, after enrollment in the school/center, they developed social skills along with education. As a result, they developed a disciplined routine like waking, sleeping, doing their lunch and dinner. Moreover, they even spared time for sports".

As far as the social skill training was concerned, all the institutes were running under the umbrella of one directorate and were supposed to provide uniform services. However, it was observed in this study that there was variation in the type and quality of services across institutions. In some institutes, the quality of social skill training was very efficient while in the others, it was not effective. For examples, the Centre for

[12] The term mental retardation (MR) is used instead of Intellectual disability in official documents in Pakistan. The names of the different centers also depict the same term i.e., "Centre for Mentally Rerated Children".

Physically and Mentally Retarded Children in *Haripur* was focusing only on academic training like reading, writing and memorizing without considering the type of intellectual limitation of children. The officials of the same institute justified such negligence with non-availability of special education teachers, social case workers or psychologists. It was observed that there was a sole psychologist in the entire directorate who was working in the same institute in *Haripur* but was responsible for the management and administrative affairs instead of social skill training. As a result, as a psychologist, she could not conduct assessment as well as other social skill trainings as she was mainly responsible for administrative responsibilities.

On the other side, a section for children with ID at Special Education Complex, *Hayatabad* Peshawar was extending a variety of services. The reason of this state of services in *Peshawar* was revealed by the officials that the institute was following the rehabilitative model of Federal Directors of Special Education, Islamabad, which was part of the same setup, however, devolution in provincial setup in 2011 in the wake of amendments in the constitution of Pakistan called as 18th amendments. For verifying the nature and quality of the same services, the researcher paid visit to the National Centre for Mentally Retarded Children, Islamabad and found the actual model of social skill training. Normally, it was found as an established fact that special education Centre working under the provincial directorate provided in-effective and poor standard of social skills training. Such poor state of services was described by a social case worker during in an Individual Interview at the Centre of Physically and Mentally Retarded children, *Bashir Abad:*

> "Children with ID require daily life skills, however, we provide them normal education due to lack of special education teachers in the centres. Furthermore, the teachers who are working here encounter multiple job problems such as low salary, no job structure, etc. As a result, they take less interest in the training of such children".

A Director of Special Education Complex as well as Principal of the Section for Mentally Retarded Children shares his opinion about the social skill training of these children during an Individual Interview in *Peshawar*:

> "As far the social training of these children is concerned, we provide daily living skills to these children by involving them in small activities like washing hands, skill of eating, using toilet and how to behave on different occasions. The purpose of such activities is to evolve the spirit of self-help among children and make them independent".

According to the Social Case Worker at the Special Education Complex, *Mardan,*

> "We have four types of children with disabilities i.e. mentally retarded, blind, deaf and physically handicapped. As far the prevalence of disability is concerned, the ratio of children with impaired hearing is higher as compared to other disabilities in Mardan. We have no as such facilities for such children, however, there is a private institute which has maximum number of such children. The second highest ratio of disability among Children in Mardan is mental retardation".

Hence, the quality and extent of social skill training was low and these institutes were mostly focusing on normal education such as reading, writing and learning, though, children with ID could not benefit from such services. They required daily life skills for living independent life which was lacking in most of the institutes in the province.

6.4. Physiotherapy Services for Children with ID

Physiotherapy is one of the most important services for the rehabilitation of children with ID. Physiotherapy is a type of exercise and treatment through which the child with physical and intellectual disability is treated to overcome their physical defects. Such treatments or exercises are manual as well as electric.

It was observed in the course of this study that physiotherapy services were available in all institutes as compared to other services. Initially such institutes were established for focusing on physically disable children while little attention was paid to

other kinds of disabilities although children with ID constituted a substantial number of population in Khyber Pakhtunkhwa, no holistic program for their rehabilitation existed in the province so far. The only hope for such children and their parents was the insufficient and urban-based special education centre in the selected districts of the province. Such centres were short of trained staff and latest assistive technologies required for the rehabilitation of such children. They had been established in 1980s by the President of Pakistan, General *Zia ul Haq* whose daughter "*Zain*" suffered from physical disability. Thereafter, no result-oriented services and institutes were established in the country. The same state of services was described by almost all staff members, most importantly, the physiotherapists at different Special Education Complex. For instance, a Physiotherapist shared the same state of services during an Individual Interview in *Hayatabad Peshawar:*

> "The equipments installed in all the institutes are completely useless. We need modern technologies for various therapies of such children".

Another Physiotherapist at Special Education Complex, *Mardan* shared during an Individual Interview:

> "For effective physiotherapies, we need modern equipments of physiotherapies, here we are restricted to vex therapy and muscle relaxers, though, hydro therapy, roll ball therapy, steam therapy etc. are required which are not existent. We rely only on outdated techniques of physiotherapy".

Though children with ID required other services like speech therapies, auditory therapies, social skill training as referred above, vocational therapies, behavior therapies etc. However, these services are non-existent due to lack of recognition ID as social problems in the province. The Government at both Federal as well as Provincial level are ignorant about the high prevalence ratio of ID due to lack of regular official census in the country.

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On the other side, the parents who approached the special education centres, send their children for provision of breathing space for managing household activities as they required full time care.

6.5. Special Education as Service for Children with ID

Special Education was considered as another important service available for such children in different Special Education centers in the province. Special education is a specialized form of education in which the children are taught through a specialized and skillful methods and techniques such by using braille, so that, they can learn effectively like normal children in schools.

As far the training and development of such children are concerned, it was found that all institutes were primarily focusing on literacy and learning such as alphabets, numbers and books instead of daily life skills. However, such children needs daily life skills like how to eat, keep themselves clean, behave, toilet using, wearing clothes etc. instead of education. Though some of the scholars conceptualize education in broader sense which encompasses both literacy and skill oriented training but it was found that the institutes were operating in the form of reading and writing.

This state of services was shared by Head of such institute, as key informants during in an Individual Interview in *Peshawar:*

> "These institutes/centres provide employment-oriented education to such children which is not beneficial for them as they cannot learn due to limitation in learning, they need daily life skills, how to live an independent life and not else".

The same opinion was endorsed by another senior official of the Institute during in an Individual Interview in *Haripur, Mardan* and *Nowshera:*

> "We have developed a wrong concept of special education for children with intellectual disability instead of rehabilitation. They need social skill training rather than education. They cannot learn a page of basics. An official asked me

some weeks ago during his visit to this centre that was there any curriculum being followed, I replied that no, these children just follow basics of education".

As far as the special education of such children is concerned, the institute has categorized intellectual disability according to its severity. For instance, mild intellectually disable children are assisted to learn alphabets up to fifteen. Similarly, they are also assisted to read and write simple words, so that gradually, they increase their vocabulary by relating learning with things and activities of their daily life.

The other type of children with ID are known as slow-learners who are good in their daily performance. They can learn up to primary level, however, they are helped to read and write simple words. They are also enable to differentiate colors, shape, and size and solve simple puzzles etc.

While, the third type is such children are known as severely intellectually disabled, who need training in keeping themselves clean, clothes, can tie their laces, wear and change their dresses. Moreover, they are also trained to cross the road, know their names and can recognize their parents etc.

6.6. Vocational Training for Children with ID

Besides other important services as referred above, vocational training was found as another important service delivered by some institutes for the training of children with ID. Vocational training which are consists of artistic activity like canning, gardening and sewing clothes.

The aim of these training is to make children with ID skillful and self-supported. Such vocational trainings range from cutting & sewing, chick making, canning and Embroidery. However, such trainings were limited to slow learners and children with mild or moderate ID.

It was found in this study that such trainings were functional in two centres only i.e. *Hayatabad* and *Mardan*, while the rest of the institutes were lacking it. There were many reasons for such non-provisions which were shared by different officials. For instance, the lack of such services was shared by a Head of the Institute during in an Individual Interview in *Nowshehra,*

> "We do not have trained and professional vocational trainers in the institutes. Moreover, initially there was a trainer, but, he was not expert in his field as result his role was not very effective. As children with ID cannot learn through simple ways rather needs more sophisticated and modern techniques".

As discussed earlier that such trainings are more effective and helpful for children with mild ID or slow learners as they can be socially trained, educated up to limited level and could also be equipped with vocational trainings. As a result, they can live an independent life. However, due to non-availability or least effective trainings, such children are deprived of its benefits.

The same shortage of important services was shared by another official during in an Individual Interview in *Peshawar:*

> "The posts of vocational trainer are vacant in this institute. We have written to the Directorate for provision of vocational teachers but so far no action has been taken. The reason of this indifferent attitude is 18th amendment, when most of technical staff transferred themselves to their native areas as a result a vacuum of such professional was created. Now, the directorate is unable to fulfill this vacuum".

Hence, it was found that vocational training is an important skill based activity which can make such children independent. Moreover, such trainings can also overcome the sufferings of their parents. However, the non-availability of such services affects both children and their parents.

6.7. Free Transport Facility for Children with ID

Availability of free transport for pick and drop is an important service which enables the parents to send their children to such schools. Keeping in view the special needs of children and financial conditions of their parents, the government provided limited facilities of free pick and drop from appropriate points.

It was observed that most of the parents were not able to afford exclusive transport facility for their children; hence, such facilities enable their children to participate in the school/center. Though, some parents complaint for shortage of transport facility. Reflecting upon the same service, Heads of the Institute shared their views about transport facilities during Individual Interviews in *Peshawar* and *Haripur* as:

> "We provide free transport facility with the aim to enable parents to send their children without any hurdle. Though, the number of buses is limited".

It was observed in this study that most of the parents having children with ID were financially weak. If the same facility was not available, they might not have send their children to such institutes.

However, it was observed that such facility was satisfactory in some institutes while in other there were limited facilities of transport. For instance, special education complex *Mardan* and *Peshawar* have enough buses for pick and drop of both ID and children with other disability while in Haripur, *Noweshera, Bashir Abad Peshawar*, there was only one bus which provided transportation to not only children with ID but to other children as well. Moreover, pick and drop facility was restricted to urbanized location and children coming from far flung areas were drop in far-away point due to which such children and their parents were faced with facility problems.

Part: 2

6.8. Official Perspective Regarding the Effects of Services on the Families

6.8.1. Counselling of the parents/enhancement of self-esteem of the parents

The birth of the child with ID carries a substantial amount of pressure for the parents and families. They suffer from emotional setback, guilt feeling, stigma, social and economic agonies. When parent approach to such institute for admission of their children, they have guilt and depressive feeling. They consider themselves as the misfortunate parents. However, admission in the institute provides counseling and therapies opportunities to such parents which help them to overcome their depressive feelings. The same positive impact of admission of such children in special education Centre was shared by the Director of Special Education Complex, *Hayatabad*, during in an Individual Interview:

> "We give them visit and tell them that you are not the only ones, there are many people who extend primary care to such children without any hurdle. We also tell them that you are the gifted parents of Allah, Who will reward you both in this world as well as in the other world. Consequently, they develop the same feeling as they have for their normal children".

Moreover, some of the Institutes have established an association of parents called as Parent Teacher Association (PTA) which had regular meetings for sharing their progress. In such meetings, they share the strengths and weaknesses which assist them to develop coping abilities. Most importantly, the admission of their children provides special relief to the mothers in managing their house hold activities. For instance, the mothers of Autistic children suffered a lot due to full time involvement with them for feeding, toilet and behavioral issues. The fathers of such children mostly go to their work while mothers usually stay at home as primary care givers. Moreover, children

with ID need extra time and resources as compared to other normal children. Financial burden is mostly borne mostly by the father while the care-giving burden is usually borne by the mother. It was also discussed previously that due to extensive care-giving, the mother feels extremely overloaded and faces social exclusion in society. However, it was observed that enrollment in the school provided them an opportunity to give time to other household activities and community ceremonies. Hence, after admission, the mothers of such children get relief for four to five hours.

The importance of child's enrollment for the mothers was shared by the Director and Principal of Section for Children with Mental Retardation in *Peshawar* during in an Individual Interview:

> "We realize the importance of this relief during summer vacation. Parents often call and ask for the opening of schools as they are completely stuck with such children".

The same effect was shared by a social case worker during in an Individual Interview in *Peshawar* and *Haripur:*

> "Such children need extra care as compared to normal children for feeding, cleansing, and using toilet. Moreover, parents are supposed to keep eye on them during their play time with other children, as they show aggressive behavior and also quarrel with their siblings. Hence, in the presence of such children, the mothers are unable to carry out other household activities. Their enrollment in the center/school has provided them with breathing space to fulfill other household tasks."

Hence, admission of child not only benefits but also provides psycho-therapy to the parents by interacting with the special education teachers and social case workers. Moreover, these institutes also provide breathing space to the mother in family life in managing other house hold activities. The same feelings were shared by the officials of different special education centres as well as parents of such children in different interviews.

6.8.2. Official's Perspective about Institutional Problems

In the previous part of this chapter, various facilities and services were discussed while this part describes different problems faced by the officials and staff members of these institutes.

6.8.2.1. Negative effects of 18th Constitutional Amendment on the special education and social welfare sector of Khyber Pakhtunkhwa

In Pakistan, there were two types of administrative structures of Social Welfare and Special Education i.e. Provincial Directorate of Social Welfare and Special Education and Federal Directorate of Social Welfare and Special Education. The provincial setup was governed by provinces while the federally run institutions were supported by the Federal ministries. As far the strengths and weaknesses of both setups were concerned, the provincial directorate of social welfare and special education was fragile in terms of resources and job structure. On the other hand, the Federal Directorate was governed by the federal ministry which was very resourceful and its departments and directorates were prevalent in four provinces of the countries. However, after amendments in the Constitutions of 1973 of Pakistan in April 2010, those federally administered institutions which existed in provinces were merged with provincial administration. Such amendments in the constitution are known as 18th amendments. Hence, besides other institutions, social welfare and special education was also devolved to the province of Khyber Pakhtunkhwa on April 1, 2011.

The 18thamendment has badly affected those special education institutions which were affiliated with Federal directorates and later on merged with provincial directorate which was already confronted with shortage of funds and feeble organizational and job structure. Such devolved institutions had not been integrated in true spirit by the provincial administration. The employees of federal directorate were initially receiving

deputation allowance. However, due to these amendments, they were also deprived of this facility. Consequently, the employees were encountered with multiple problems which had trickledown effect on the services for children enrolled in the institutes. Such state of transition of special education was shared by the Senior Official of the provincial setup during in an In-depth Interview in *Peshawar* that:

> "Those Special Education Institutions which are devolved to provinces are still floating in the air, neither federal government accept them nor provincial setup. A result they have become "*Adha theethar adha bateer* [half a partridge and half a quail]".

The same senior official was describing the after-effects of constitutional changes during the same Individual Interview in *Peshawar:*

> "Presently, provincial setup is not accepting them, consequently, a developed sector have been converted into under-developed sector."

A Director of Special Education Complex (senior official) who was also an affectee of the same constitutional changes, shared his experiences of the new setup during in an Individual Interview:

> "When I was appointed as Director Special Education Complex, I was supposed to focus on the services for children with special needs but the Chief of Social Welfare directorate who is by designation a Director, forced me to facilitate his official functions and meetings instead of catering to the needs of children. These meetings used to take place in our institute as they did not have a conference or meeting venue in the directorate. When I resisted it, I was transferred back to out-station area".

Moreover, there were established staff training Institutions for the employees of special education. However, after devolution, they were deprived of such professional grooming as there was no training Institution at Provincial level for in-service job.

The after-effects of the 18th amendments was shared in very disappointing tone by a special education teacher at Special Education Hayatabad during an Individual interview that,

> "Before this amendment, we had an opportunity of nationwide exposure at NISE which was a training institute where we developed our professional skills and also had interactions with different people. Some employees who attended foreign trainings used to deliver lectures and share their experiences with participants at NISE. Now such national and foreign level training opportunities have been curtailed".

Furthermore, this amendment has caused conflict of interests among the management staff. For examples, there are two Directors of the Special Education Complex at *Mardan* and *Peshawar* who are in grade 19 while the Director of the Directorate of social welfare and special education is also in grade 19 who is leading the whole sector. As a results, such senior officers are now working under the authority of either equivalent or lower grade officers. Moreover, the District is now headed by the District Social Welfare Officer which was either in grade 17 or 18 who was also considered as the boss of the Directors' of grade 19 new setup. Hence, such issues were causing clash of interests and litigation among the employees of the department.

A senior official of Special Education Complex shared his problems that,

> "I am in grade 18 at the moment, if 18th amendments had not been introduced, I would have been promoted to grade 19. Now, I am on top of the list but there is no sign of promotion".

The same state of confusion and conflict was narrated by another Special Education Teacher at *Peshawar* during an Individual Interview:

> " Promotions of the employees have been stopped and the service structure has been ended. Before amendments, the federal special education had 36 officers who were in grade 19 while in the provincial setup, there was not a single employee in grade 19. Here in the province, provincial Chief of social welfare was in grade 18 while there the Head of every Centre was a grade 19 officer".

Another senior official of the Special Education Complex who was also affectee of the said amendments shared the financial affects during an Individual Interview in *Peshawar:*

> "Due to 18th amendment, budget of such institutes have been curtailed. For instance, a school bus is standing in park for the last three days due to non-

availability of funds for repair and maintenance which has curtailed the education of almost 50 special children. For this purpose, when we informed the director about the situation, he replied that let it be stopped till the release of budget".

Another senior official of the Special Education Complex shared the adverse effects of 18th amendment during in an Individual Interview in *Mardan:*

> "Before 18th amendment, there was a regular white wash and maintenance of the building on annual basis. However, 4 years have passed, and there is no white wash in the building. As a result, the building is getting out of order".

Besides this, the 18th amendment has also withheld the various allowances of the devolved employees. An official shared:

> "I was residing in rented house for which the department was paying me Rs. 15000/- as house requisition, which has been stopped now. Moreover, we were entitled to medical treatment at FG Hospital at Shami Road Peshawar, where we received free treatment and medicine, however, after 18thamendment, such facilities have been abandoned".

The provincial Directorate of Social Welfare and Special Education Peshawar is a central department for the rest of social welfare and special education institutions in the province. The sector is encountered with multiple problems like lack of holistic policy, poor governance, weak organizational structure and lack of human resource development. Hence, it is considered as the weakest department in the province and that's why it has always been limited in its volume. After devolution, the federal special education institution was put an additional burden on shoulders of an already weak department. Though the sector received ready-made assets in the form of building, vehicles and employees but could not get the system. Consequently, it has converted the developed sector of social welfare into underdeveloped sector. Those employees who used to be the most efficient members were stuck in organizational issues. As result the role and services of the institution have been badly affected, which untimely affected the rehabilitation of child with ID and resulted in agonies for their parents.

6.8.2.2. Shortage of Trained and Qualified Staff of special education

As discussed in detail in part 1 of this chapter, rehabilitation of children with ID is a multidimensional process which is carried out by a team of professionals with different academic and professional backgrounds. For instance, a social case worker conducts pre and post admission assessment of child's disability and socio-economic status and keep liaison between school management and parents. Similarly, special education teacher imparts educational skills to special children according to their special needs and intellectual capacity. Therapists (physiotherapist, speech therapist, auditory therapist etc.) make effort to treat their physical, verbal, hearing and cognitive defects by using their skills and knowledge. Moreover, vocational and occupational trainers impart such children skill-oriented training according to their intellectual capacities. Hence, qualified and trained professionals can make this huge task possible. In case of non-availability of such professionals, the rehabilitation of such children can be affected and consequently, it might cause permanent agonies for the parents and their families.

It was observed in this study that the special education centres were running without qualified staff which was badly affecting the social training and rehabilitation of such children. Such institutes had teachers and other staff who were supposed to be graduated in special education and other relevant areas like visual, hearing, speech or physical therapies. Furthermore, no speech therapists, medical doctors or clinical psychologists were found in any of the institute who can play a very important role in therapy and rehabilitation of such children. Majority of the teachers were trained in other disciplines like literature, law or other irrelevant subjects. It was found through informal discussion with the staff members that social welfare and special education is the easiest sector where political appointments could be made.

For example a physiotherapist who was acting as Head of the Institute shared the problem of shortage of staff members during in an Individual Interview in *Nowshera:*

> "We do not have trained teachers. At the moment we have only one special education teacher who teaches *Islamiyat* (Islamic studies) to them, she is not a qualified special education teacher. She has no formal training related to this field".

When the head of the same Institute was interview on the next day about the shortage of staff, she shared her experience as:

> "We have sanctioned posts but not filled by the directorate yet. We need speech therapists and doctors. We have deaf and dumb children, though we have no experts for dealing with them. We have admitted these children here because there is no such institute elsewhere to deal them"

The shortage of qualified staff was not restricted only to one institute or Centre, rather it was observed in all special education schools/centres. For instance, the Head of the Centre for physically and Mentally Retarded children in *Bashir Abad Peshawar* has shared the detail of the staff members during in an Individual Interview:

> "We have ten staff members in this center, out of which, three are a females. However, out of this total only one teacher is qualified in special education while the rest of the staff members are either simple graduates or have post-graduation in other irrelevant subjects like literature with no training in the field of special education".

Another Head/Manager of the Center for Physically and Mentally Retarded Children at *Haripur* reflected on the students-teachers ratio during an in Individual Interview as:

> "I have only 4 teachers in this center for dealing with 60 children, which constitutes a teacher-student ratio of 1:20 against the international standard ratio of 1:06. Moreover, none of our teachers are qualified and trained in special education".

On the other hand, the parents were complaining of the methods of teaching-learning process. For instance, an educated father was sharing his reservation during in an individual interview in *Haripur:*

> "Most of the teachers are teaching from the books designed for normal children. They teach alphabets and other related topics through normal teaching methods. But I personally believe that such children need social skills training rather than

academic training as they have limited learning abilities. I do not know the logic behind this approach".

Another very important finding observed during field work of this study was that there were no places in such institutes for children with severe intellectual disability. Though, such children were supposed to be given more time and facilities in such institutes, but due to shortage of staff, the institutes were not welcoming such children. When the same issue was discussed with a special education teacher in *Mardan*, he shared a very important point that for dealing and managing such children, such institutes need *Ayaaa* (female attendant) in each class room which was not provided by the directorate so far.

> "We have severe shortage of *Ayaaa* (Female attendant) for managing children with severe ID".

Hence, children with severe ID are not treated and rehabilitated in any such institute in the province, which is a permanent cause of suffering for their families and parents. In short, it was also found that social welfare and special education ministry in Khyber Pakhtunkhwa was one of the weakest sectors as compared to other sectors like education, health etc. Consequently, the sector faced extreme shortage of funds, equipment, trained human resource and infrastructure.

6.8.2.3. Shortage of Funds and Equipment

Another major problem observed during interaction with the official was that there is shortage of funds due to which purchase of furniture, equipment for therapies, vehicles for transportation, medications, sports items and other related facilities are not possible. Due to these persistent deficiencies, the sector of special education and social welfare was called as the neglected and dying sector in the province. Though, the

number of children with ID is increasing day by day, which was shared by the officials and parents. However, the allocation of resources is equal to none.

The problems of shortage of funds was shared by the Head of Centre in *Peshawar* during in an Individual Interview:

> "We are facing shortage of funds every year. Sometime sanctioned funds are released 4 to 6 months late due to which the pick and drop of children is endangered. However, I pay the same expenditure i.e. fuels from my own pocket and annually the department remained my defaulter. I am paying this amount just because I myself am mother of a child with physical and ID. I can understand the importance of such schools and training for such children".

Due to shortage of funds, the children in the centres were deprived of the most important service of speech therapies. Those children who were suffering from Autism (a type of intellectual disability) needed speech therapies but speech therapist was not available in the two centres. Moreover, parents were unable to afford speech therapies at private level as such experts charge 600 rupees for each session of therapies. Such children need continuous therapies for at least two or three years. The same problems were also reflected by parents during individual interviews and FGDs and seriously complained of the lack of speech therapists and associated technologies for treating their hearing abilities. As a result, the learning abilities of these children were growing very slowly. When Head of the Institute was contacted and asked for the non-availability of the same problem, she shared her experiences and feeling during an in individual interview in *Peshawar:*

> "I am serving this institute from the past fifteen years and besides other requirements, speech therapy is one of the most important needs of children with speech and mental retardation. I have personally raised this issue in different meetings with Secretary and Director Social Welfare but they were silent due to meager financial resources. On the other side, we have a permanent physiotherapist who provides physiotherapies to children, though, the modern and latest equipments for physiotherapies are not available".

Shortage of funds was observed as the major obstacle in providing necessary services to the children. Speech therapy was found as the most inevitable need of children which has completely made the institute and the staff members handicapped.

> "Before 18th amendment, there was white wash and maintenance of the building annually, now from the last 4 year we have not managed this, though, we are frequently writing to the Worked department, but no step has been taken so far. Financial constraint is the big impact of 18th amendment".

Hence, shortage of funds makes these institutes deficient of assistive technologies and equipments which are needed for physiotherapies, vocational training and speech therapies etc. Consequently, the rehabilitation of such children is badly affected which causes agony for their parents.

6.8.2.4. Lack of Service Structure for the Employees

Besides other limitation, lack of service structure was observed as one of the major problems which was affecting the efficiency of the centres. They were seriously complaining of the lack of promotion from one grade to another grade. As a result, the staff members were not taking interest in the job. Consequently, the children with disability were getting training and education without any social training and therapies, which were affecting the re-integration of such children into society. The problem of lack of job structure was shared by the Head of the Special Education School/Center *Bashir Abad* in *Peshawar* in an Individual Interview:

> "I have served this department for 26 years and will retire in grade 18 next year. My class fellows who joined other departments in the same year will retire in grade 20 and 21 but due to lack of job structure, I could not get promotion. This problem is not only affecting the efficiency of the staff members but also blocking competent human resource to be inducted. Similarly, those staff members who were competent left the institute and joined other departments".

The same problem was sharing by the Principal of the section for mentally retarded children in Special Education Complex in *Hayatabad Peshawar* during an Individual Interview:

> "After 18th Constitutional amendment in Pakistan, those Federally Administered Departments which were working in different provinces were merged with provincial ministries. As result, special education fell in the domain of provincial government. Previously, we were enjoying job satisfaction due to availability of funds, other facilities and proper job structure, but after merging, we are facing serious problems of funds, facilities and job structure. All the staff members are worried about their future which is badly affecting their efficiency as well".

Hence, the lack of job structure was observed as one of the major problems, which was directly affecting the services for children with ID. Moreover, the condition of the officials previously working under the federal directorate of special education was much better. However, decentralization of the federal social welfare and special education, as a result of constitutional amendments called 18th amendment, has added hopelessness in the professional life of the officials.

6.8.2.5. Lack of Social Welfare Policy and In-service Training for Staff of Special Education and Social Welfare

Before devolution, it was the subject of the federal government and we were following the initiatives till 2011, but no proactive policy existed even there. However, now it has become the domain of the provincial government to have an integrated social welfare or protection policy. As far the policy is concerned, this department has developed segments of policies for each wing of the services, particularly, they are involving to formulate a policy for persons with disability and women empowerment.

> "My opinion is that there should be an integrated single social welfare policy encompassing the needs of all segments of the society".

It was also observed during frequent interaction with different officials of the special education and social welfare department, that there was no social welfare policy except the 21 year old social welfare policy of 1994. The lack of dynamic policy badly affected the needs and services of children with disability. Children with ID as well people with other problems were also deprived from social services due to static policy

in country. As a result, the sector of social welfare and special education is running with outdated policy of social welfare of 1994.

Furthermore, there was no training opportunity for the employee of special education at provincial level. It was observed in this study that provision of pre-job training and mid-career training was mandatory for professional grooming and promotion; however, there was no such training and capacity building opportunity. As a result, the staff members were living with outdated skills which was affecting the services for children with ID. Discussing the same problems, a Social Case Worker at the special school/center at *Bashir Abad in Peshawar* shared his experiences during an in individual interview:

> "At provincial level, there is no training institute, however, there is a training institute at federal level called as the National Special Education Training Institute. Being an employee of Special Education School and Social Case Worker, I have received only two trainings related to assessment and therapeutic games during my career through my personal effort. Teachers are not willing to avail such training as they see no benefit for their career. Moreover, the female teachers avoid such training due to cultural constrains as they cannot move and pass nights outside the home".

Discussing the issue of training and capacity building with the Head of the Centre for Physically and Mentally Retarded Children at *Haripur,* she shared her experiences during an Individual interview:

> "I am serving this institute for the last 7 years during which I have not attended any training workshop related to disability and mental retardation. Similarly, the other teachers have not attended any training related to their field. Probably, it is due to a long distance from the provincial directorate as we have never received nominations for such training. As a result, the staff members follows outdated techniques of teaching and therapies".

Besides lack of up-to-dated social welfare policy, the special education teachers and officials were complaining of the lack of capacity building opportunities. Such poor state of affairs was directly affecting the services required for the training and rehabilitation of such children.

Furthermore, parents who were more ambitious about the future of their children were also shown concerned about the poor state of social welfare and special education.

6.8.2.6. Neglected Attitude of the Parent

Parents and staff members at the Centres are important stakeholders in the training and rehabilitation of children with ID who make it possible through proper cooperation and coordination.

However, it was observed in this study, that both parents and the staff of the centres have poor coordination in this regard. The parents were blaming the staff and Centres for poor services, while the staff members were blaming the parents for their non-cooperative attitude and negligence regarding their child's education. The staff members were sharing that parents once admitted their children in the centre never turn back as they considered admission of their children as relief in their life. This problem was reflected by the Principal of the center for Intellectually Disable children in *Hayatabad* Peshawar in an Individual Interview as:

> "As far the interest of the parents is concerned, I observed that most of the parents are least interested in training and rehabilitation of their children. After admission of their children, they never pay follow-up visits to the Centre for knowing the status of their children".

Similarly, a Social Case Worker at the Centre for physically and mentally retarded children at *Peshawar* was sharing his own experiences during in an Individual Interview as:

> "I have observed that children with ID are burden on the parents. They admit their children with the intension to throw away a burden. As result, they never visit or pay call for knowing about the growth and development of their child after admission in the school. However, some parents are extremely conscious about their children and maintained regular contacts with the centre".

Summary

Parents-teachers coordination for the training and development their children with ID is extremely necessary and important. Parents focus on the development of

overall personality of their child, while special education teachers concentrate on the development of social and cognitive skills and overcoming their weakness through their professional interventions. However, the parental and special educational teachers' role was found ineffective in obtaining the desired objectives. The parents complained of the neglecting attitude of the teachers and less conducive environment at the special education center/school in both districts i.e. *Peshawar* and *Haripur* where this study was carried out.

On the other side, the teachers and staff members have accepted that they were not competent enough to provide them an ideal environment for their children, though; they are trying their level best to focus on the children. They have associated the weak performance with administrative and governance issues which had handicapped them to deliver quality services. This negligence and other problems were due to non-availability of funds, shortage of qualified teachers and therapists, lack of job structure and no training opportunity. Furthermore, they were also blaming the parents for their irresponsible attitude. Most of the parents have never contacted the school/center for knowing the condition of their children.

CHAPTER 07 ANALYSING EFFECTS OF CHILDREN WITH ID ON FAMILIES AND INSTITUTIONS' ROLE IN MITIGATION OF ADVERSE AFFECTS

The previous chapter presented the views of parents regarding the effects of child with intellectual disabilities on families such as social exclusion, family disorganization, family-work conflict, family displacement, verbal abuse, extra financial burden and psychological distress, while chapter VI presented and explained the views of officials regarding the institutional role in children's rehabilitation and mitigation of parent's sufferings.

This chapter, however, juxtaposes such explanations and observations with secondary data so that the effects of such children on family are analysed along with related literature, and results are derived. Furthermore, this chapter in brief analyses the effects of children with ID on the family and the role of officials in mitigation of sufferings of such children.

To facilitate overall understanding and likewise ensure coherence in the overall argument of the chapter, this chapter is divided into two parts. Part-I analyses the causes of effects of such children on the parents and family members, while part-II explores and explicates reasons of failure of institutions in lessening the sufferings of the parents.

Part-I

This part, as referred above, examines the causes of the adverse effects on the family, and most importantly on mother (as primary care giver) which have links with patriarchy in family care giving, superstition-induced-behavior regarding ID, and courtesy stigma. As it was referred above that mothers were the most worst affected segments of ID of their children which were due to the prevalent social structure in

Khyber Pakhtunkhwa based on patriarchy. As far the concept of patriarchy is concerned, in simple words it refers to the male domination in the social and domestic affairs of family (see Christ, 2013: 86). These concepts and practices are analyzed in detail in the following section.

7.1. Family and Patriarchy: Adverse Effects on Mothers as Primary Care Giver

Family is a social network, which is constituted of experiences and expectation of its members (Hanney & Kozlowska., 2002). "What families value and believe in are reflected in the ways families behave, especially in the ways they enact their roles with each other. What men are expected to do and to be (or not), whether women are expected to be supportive but dependent, and how much adults are thought entitled to deal aggressively with children, are all clearly demonstrated in family life" (Hattersley, *et. al.*, 1987).

Women role in traditional societies is limited to family care-giving as compared to the earning role of men. Such dichotomy is due to the patriarchal structure of society. Patriarchy refers to "social organization marked by the supremacy of the father in the clan or family in both domestic and religious functions" (Feeley, 2010:1). It is characterized by male domination and power (Hooks, n.d.). Consequently, women not only bear the burden of unpaid household work (Coontz, 1970) but also bear the shock of the birth of the child with intellectual disability in the family (Wilson, 1977). The birth of such children have evident effects on parents in general ,and mother in particular ,and cause social, psychological and economic agonies for them (Majumdar, Pereira and Fernandes, 2005).

Mostly, mother is negatively affected because she is often the sole care taker of her child. Such burdens isolate her socially that triggers "cycle of rejection" (Chenoweth

and Stehlik, 2004: 59-72). Such rejection is due to too much involvement in the demands of the disability to be able to build external social capital resources. Consequently, she experiences health related problems, career adjustment problems, especially for working mothers, and some time experiences loss of support from the spouse (Rashid, 2010). Loss of support of spouse demonstrates negative emotions like 'despair', 'blaming each other, especially wife', 'comparing child with normal children', which disrupts their routine activities' and 'interpersonal relationships' (Singh, Indla, & Indla, 2008).

The same discriminatory effects on mothers in the family were found in this study which were mostly negative. The agony of the mothers' starts from the birth of the child, however, shares, absorbs, transfers and heals in joint family. Moreover, support in joint families provides psychotherapy and emotional support to such affected mothers in traditional and agrarian societies like Pakistan. The reason of reliance on the family is due to the less supportive role of state in provision of public assistance. Hence, family provides welfare to the needy due to inability of the state machinery and poor economy.

On the other hand, over-reliance on the families breeds social problems as well. For instance, it preserves and maintains fixed role in society which promote patriarchy, which means gender imbalance in role. Hence, this over-reliance on families is discussed in detail in the next section 'Family as Welfare Agency' below:

7.1.1. Family as 'Informal Welfare Agency' for the Support of Children and their Parents

Social Welfare also refers to the "organized societal activities aimed at maintaining or improving human wellbeing" (United Nation Organization, 1963: n.d). Similarly, United Nations Organization (UNO) describes "social welfare as a wide range of socially sponsored activities and programs directed towards community and individual well-being" (United Nation Organization, 1963: n.d).

As far the sources of social welfare are concerned, it is normally believed that there are four sources of welfare provision such as state welfare, private welfare, the voluntary sector and the informal welfare like family and community (see Johnson, 1999). The state welfare refers to direct provision of welfare services through public welfare programmes under the guidance of social policy, planning, regulation and finances (See Schwartzmantel, 1994). While "private welfare refers to private income-maintenance expenditures or payments made under employee benefits plan under private pension plan, group insurance, cash disability insurance, paid sick leave, and supplemental unemployment benefits (Kerns, 1994:3)."

Whereas, the voluntary sector refers to a civil society, which is normally considered as the third sector, "the voluntary and community, non-profit, not-for-profit, charity, social and even beyond profit sector. It is made up of many different categories of activity affecting many aspects of society (Hogg, 2015: 576)." Informal welfare refers to "the sector which provide informal care to the dependent people and everyday care for able-bodied people arguing for a broader and more critical perspective, which locates informal care within the context of the wider caring work that goes on in households (Graham, 1991: 1)."

Family and community constitute informal welfare sector in the society. As far the existence of informal social welfare is concerned, it is found that societies where state intervention in welfare activities is either selective or limited, family then play an important role as a social welfare and social security agency. Consequently, family provides support to both well-off members as well as to vulnerable segments of society such as children, aged people, ill, and unemployed.

In more advance societies, institutions provide services and support not only to children with special needs but to all members through various institutions such as

public assistance program

(Mclinnis-Dittrich, 1994), they follow developmental (Midgley & Livermore, 1977: 574) and institutional model of social welfare (Mclinnis-Dittrich, 1994) wherein protection of all citizens is the primary responsibility of the state, not of the family. On the other hand, in traditional societies like Khyber Pakhtunkhwa, residual types of social welfare existed (Ryan. 1971) which is based on the conservative philosophy of social welfare which says that state intervenes only when needed but for short time (Popple and Leighninger, 1999). Owing to such selective intervention, family remained as the ultimate source of support. However, there are societies where social welfare services are being provided by state, voluntary, and family welfare especially in Europe which is called "Welfare Mix" or "welfare pluralism" (Evers 1990).

In Pakistan, the practice of welfare mix based on 'conservative philosophy of welfare' has been found in different political regimes in the form of "public-private partnership" and "grassroots development" which provides social welfare to the needy only through voluntary organizations such as the Sarhad Rural Support Programs (SRSP)[13], Edhi[14] Foundation, Dost[15] Foundation, Aurat[16] Foundation etc. However, such "welfare mix" remained in transition due to political transition in the country since 1950.

However, the role of family as welfare source is not sufficient for the recovery/rehabilitation of such children; rather it pushes them into numerous social and economic problems. Moreover, family support negatively affects the intellectual and social grooming of such children as they are unable to recognize their developmental

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[13] *Sarhad* Rural Support Program (SRSP) is a non-governmental organization established in 1991 in Khyber Pakhtunkhwa to carry out support to rural people through participatory approach.
[14] *Edhi* is the last name of *Abdus Sattar*, a renowned philanthropist in Pakistan and running a self-support charity institution '*Edhi* Foundation".
[15] *Dost* is an Urdu word means 'Friend', *Dost* foundation is non-governmental organization established in 1992 in Khyber Pakhtunkhwa for the rehabilitation of drug addiction.
[16] *Aurat* is an Urdu language word means "Woman", *Aurat* Foundation is a non-government organization established in 1986 in Pakistan and working for the women rights in the country.

needs. Almost the same explanation was given by a mother in a FGD in *Haripur.*

> "A single intellectually disable child requires care that is equal to the care of almost four children, as he/she faces difficulty in wearing clothes, eating and mobility due to which such children stay at home for most of the time. As a result, the mother is also required to stay with her child. Consequently, her full-time involvement with her child creates social complaints for her from the relatives and community members for not showing presence in social events".

Institutional role in training and education of such children is much needed for the learning of adaptive skills which is necessary to decrease an individual's dependence on others, and increase their life space (Drew, 1986).such adaptive skills if not taught through formal means, his/her development will be negatively affected. However, for children who are not intellectually disabled, teaching such skills are unnecessary because they can acquire it through daily experiences at home (Drew, 1986*)*.

Explaining the importance of institutional role, the Director of Special Education Complex, Hayatabad Peshawar expressed his views about the importance of social skill training in these institutes for these children, during in an individual interview:

> "Before admission, the parents said that their children have disturbed routine in the family. However, after enrollment in the school/center, they developed social skills along with education. As a result, they developed a disciplined routine like waking, sleeping, doing their lunch and dinner. Moreover, they even spared time for sports".

The social case worker further elaborated disability-wise services in detail during in an Individual interview in Peshawar:

> "Children with mild mental retardation are helped to learn alphabets and counting up to 15 at least. They are taught to read and write simple words. They are further helped to increase vocabulary by relating their studies with things and activities of their daily life. The children with slow learning are given education which can go up to primary level. They are assisted to read and write simple words, differentiate colors, shape, and size and to solve simple puzzles".

Hence, the role of family in provision of primary care to such children and the care giver is important, as it works as social capital for their support. Such social support and social relationship provides strength that can overcome the miseries of disability

caused either by low socio-economic background or stress. However, for overcoming their intellectual, physical, social deficiencies; institutional intervention is necessary. Moreover, the dominance of family in such welfare role also promotes imbalance in gender role (Parsons, 1932). However, institutional intervention is possible through the state oriented-welfare intervention by policy formation and resource mobilization.

7.1.2. Family preserves patriarchy in society

Families, as referred above, provide welfare services to its members where state's role is least effective such as in third world countries like Pakistan, however, such family support for vulnerable segments of society such as safety nets for the aged, infirm or other dependent kin has disappeared in modern societies such as Europe which existed at the beginning of this century" (Mitterauer and Sieder, 1982: 9). Of-course, such families provide safety net to its vulnerable segments of society but those who need institutional care normally affected negatively. Such as disable people who are deprived of institutional care.

Elaborating the child's suitability for these training, a social case worker presented his view regarding types of social skill training during in an Individual Interview in Peshawar:

> "The services to the children with MR are provided according to the type of MR. As for children with moderate mental retardation[17] is concerned, we provide them social training for keeping themselves clean, do not wet their clothes, tie their laces, wear and change their dresses. They are also trained to cross the road, know their names and recognize their parents."

Moreover, family as social welfare source exerts pressure on its members for ensuring welfare needs, consequently, some member receive more burden as compared to other. Extended families in traditional societies played multi-functional role.

[17] The term mental retardation (MR) is used instead of Intellectual disability in official documents in Pakistan. The names of the different centers also depict the same term i.e., "Centre for Mentally Rerated Children".

According to Radical feminists such as Millett (1970) "family socializes both men and women into a set of ideas which confirm male power through gender role socialization as children. Moreover, the patriarchal ideology stresses the primacy of the mother–housewife role for women and the breadwinner role for men" (8). It ensures men's domination of the labor market. Finally, Millett sees that "the family in such situation legitimizes violence against women" (Ibid, 1970: 8).

This assertion of Millet was also supported by the finding of this research, such as the mother of a child with ID shared her stress during an Individual Interview in Peshawar, who wept while narrating her experiences with depressive gestures:

> "My husband is a daily wager; he is also addicted to drugs. The child needs extra care in terms of medication and nutrition but he cannot afford it. He blames me for the disability of his child and beats me. This situation has really made me depressed and annoyed, however, I am helpless to do anything".

A mother, realizing the complaints in this regard, lamented the imbalanced role in household chores:

> "Owing to the extra care of my disable child, I am socially handicapped and cannot attend community events like marriages, death and other necessary events. I have to give time to my other normal children as well".

Though, family support in the joint family structure provides relief to mothers, however, the prevalence of joint family structure preserves patriarchy which breeds imbalance of roles (See Millet, 1970: 8). Owing to patriarchal social structure, women were found oppressed due to primary care giver role in the present study as she had to extend extra care, as required by the children with ID. Moreover, she was also held responsible for other household activities such as cooking, cleaning, washing, and other services. As a result, she was mostly suffering from role-strain which kept her away from the social and customary activities of community. Consequently, such multifaceted

with ID. In this study, most of the parents narrated their stories that they were seriously taunted for the birth of children with ID. They described that the ID of their children was considered associated with their deeds and actions rather than disability. Most of the women, as mothers, were taunted by their in-laws during domestic affairs which had caused emotional trauma for them. Such emotional abuse mostly occurred inside the family.

Sharing the same emotional abuse, a mother of such child narrated her story with extreme sorrow and started weeping during FGD in Peshawar as:

> "My In-laws taunted me that the cause of disability in the child is due to the result of my sin and God has recognized me, resultantly, I have been gifted with such kind of a child"

Furthermore, the issue of emotional abuse of mother is higher in rural and joint families with less education and awareness, though; family supports are there for child care. It was mostly reported by parents from rural areas where ID is associated with sin committed by them in the past.

Moreover, parents also shared their experiences and views regarding sarcastic remarks of community about their children with ID. Most of the parents categorically stated that people in rural areas called such children *layewanee* (*Pashtho* word mean Mad) or *chilaa* (*Urdu* world mean Mad). Similarly, the family faces fear of stigma and shame. Consequently, the parents and mothers avoid participating in social activities. Birenbaum (1970) observed in a study on courtesy stigma that social interaction between mothers of children with cognitive disability and other parents was constrained (Corrigan and Miller, 2004). Such social exclusions are due to full time involvement of mother as primary care giver and fear of courtesy stigma or associative-stigma in the society. Corrigan and Miller (2004) report that a second dimension of courtesy stigma, one that is perhaps more prominent than reports of others' discrimination, concerns the

notion that one's relationship with a family member with mental illness should be kept hidden as it is a source of shame to the family. The authors note two underlying narratives that give rise to courtesy stigma: blame and contagion. Parents, especially mothers, of persons with mental illness are most likely to experience blame as a common public perception; in the first half of the twentieth century mental health and disability were commonly regarded as the outcome of poor parenting (either unfortunate procreating or bad parenting skills) (Corrigan and Miller, 2004).

Similarly, people in rural areas also have very negative remarks and attitude about such children and often call them with different names so as to tease the CID which they enjoyed.

An uncle of a child shared his experiences of such negative remarks in an Individual Interview in *Haripur* as:

> "People attitude is not proper with him; they consider him as a source of entertainment and enjoyment. I advised people in my community that they should encourage him with positive remarks like he looks very good, and he should walk this way"

Another father shared his trouble regarding sarcastic remarks of people forhis son during Individual Interview in Haripur:

> "People tease him (child) which they enjoy by calling him mad or mental. We being parents feel extremely disturbed due to such negative attitude and remarks of people; they deal him very awkwardly".

Describing the coping strategies reviewed above, Birenbaum noticed two main responses to courtesy stigma among parents with a disable child: some parents chose to conceal, manage, and downplay stigma-related information, whereas other parents openly demonstrated their acceptance of the stigma (Birenbaum, 1970). In general, he noted that parents of children with cognitive disabilities limited their involvement with stigmatized communities because isolating oneself within the stigmatized community

tended to undermine the appearance of a *normal life* (Birenbaum, 1970).The authors note that the availability of social support networks, and other contextual variables, such as the ability of partners to draw on more positive interpretations of the illness may lessen experiences of courtesy stigma (Birenbaum, 1970).

The fear of stigma and shame are there in the family and community as the area where this research was carried out is largely driven by *Pakkhtun* customs which is based on *Pakhtunwali*[20]. Moreover, in *Pakhtun* customs, taunting or *paighog*has adverse consequences. Similarly, people mostly avoid such actions which may cause taunting for them in society. However, the birth of the child with ID is an involuntary event of stigma and taunt.

The same prevalent attitude was shared by participants in an Individual Interview in *Peshawar* as:

> *"Pukhtun*sperceive ID as sin. They even believe that families suffering from suchProblems are due to the sins they committed in their life. When people think suchchildren are a punishment of our sin, then they have negative feelings towards such children. Even they get prejudiced to them. This is start of discrimination. However, there are people who belong to religious background, they may have not committed any sin but since then, they may have such children. Therefore, it shall not be taken as a sin rather a disease which is treatable or can be decreased up to great extent".

Summary

In short, the patriarchal arrangement of family care-giving is more adversely affecting women than men. Parents face numerous problems including family displacement and disorganization, work-family conflict, and social exclusion not due to child with ID rather social barriers as explained by the "Social Model of Disability" which is supported by the feminist philosophies (Mores, 2001). Women face these issue more severely compared to men. Most of the working mothers have to quite their paid

[20]*Pakhtunwali* is a traditional lifestyle of the *Pakhtun* people which is normally characterized by honour (self-respect), *malmasthia* (hospitality), *badal* (revenge) and *nanawathi* (reconciliation) and is strongly associated with *Paighore* (taunt).

jobs so that they could provide extra care required by the child with ID. If she continues her paid job, she faces 'work-family role conflict' as she may not be able to maintain a balance between the two roles, which sometimes results in family breakdown in the shape of separation/divorce. The non-availability of effective institutional support for care of disable children in the province further increases the agony of the parents. It is also found that besides supportive role of family, it also perpetuates patriarchy and imbalance in care-giving roles. Consequently, the entire burden is put on female family members.

It is a common belief that patriarchy is a norm in Khyber Pakhtunkhwa. Therefore, as happen in a patriarchy, male have more authority and independence when it comes to caring for the disable then female. Most of the burden is put on female in capacity of mother. She goes through more agonies and stress as compared to male counter-part. In this study, mothers were found to be excluded from social activities because of their primary care-giver status. Men, on the other hand, were mostly found to be exempted from such support in both forms of families, i.e. nuclear and joint families. Nonetheless, joint and extended families were found to be more supportive to care-giving women.

Moreover, it was concluded from the discussion that ID in *Pakhtun* society is strongly associated with superstitions rather than cognitive limitation or condition caused by genetic or any other complication which could be controlled by scientific and professional treatment. Such superstitious beliefs are socially constructed which are accepted and practiced by majority of the people who are not exposed to modern education, due to their residence in rural areas. Furthermore, such superstitious beliefs are followed, due to the immediate emotional support it brings and economic affordability of such beliefs and practices. However, such superstitions mostly cause

irreversible damages to the children which result in further financial and psychological complications for the parents and family members.

Furthermore, intellectual disability among children carries social stigma for the families and parents in society due to lack of awarness. Mothers in the family are affected badly, face verbal abuse, and social stigma as they are associated with their children as primary-care givers. As a result they face associative stigma.

Mothers of children with Id are also abused mostly by the mother-in-law due to her dominant role within the family. As a result, such mothers carry the burden of care as well as taunt and verbal abuse.

Part-II

7.4. Reasons of failure of Institutional Role in Mitigation of parental miseries

In part I, patriarchy, superstitious behavior and courtesy stigma was discussed as cause of everlasting effects of ID on the family, while this part discusses the causes of failure of institutional role in mitigation of parental miseries.

7.4.1. Gap in Theory and Practice: Inefficiency of Public Social Welfare Institutions in Khyber Pakhtunkhwa in mitigation of miseries of parents having CID

This part reflects upon the gap in theory and practice of social welfare policy and social services for children with special needs in Khyber Pakhtunkhwa. In theory, the Directorate of Social Welfare, Women Development and Special Education, Khyber Pakhtunkhwa is supposed to frame social welfare policies and implement them for the welfare of the neglected, marginalized and vulnerable segments of the society. However, in practice, there is no effective policy and services for relieving the miseries of the marginalized people (disabled). To analyze this gap between theory and practice, the

following section analyses the situation of social services, facilities and problems of social welfare and special education with the help of primary, and secondary data.

7.4.2. Residual type of Social Welfare based on the philosophy of conservatism in the province

Residual type of Social welfare refers "to benefits and services supplied to only those people who fail to provide adequately for themselves and problems arise (Midgley, 2015:59)." It implies people's own fault if they require outside help. The benefits are provided until people can assume responsibility for meeting their own needs.

Social welfare in Pakistan is in-between of charity-oriented activity and professional activity, which benefits only orphans, old, and destitute women. The 1973 constitution of Pakistan held Pakistan as "Islamic Welfare State" but on the ground, there is no safety-net for the welfare of poor and needy segments of society. The state role in welfare provision is least effective; consequently, such activity is performed by family, while its benefits are restricted to short-term "help" rather than an 'enabling 'role. Though, social welfare in Khyber Pakhtunkhwa is growing like other provinces and increasing its volume and cliental day by day (Basheer, 2015), as result, government is paying attention to the sector like other sectors such as education and health.

The problems of poor Welfare system was reflected by parents views during Individual Interviews (ID) and FGDs and seriously complained of the lack of speech therapists and associated technologies for treating their hearing abilities. As result, the learning abilities of these children were growing slowly. When the Head of the Institute was contacted and asked for the non-availability of the same problem, she shared her experiences and feeling during an in Individual Interview in *Peshawar:*

> "I am serving this institute from the past fifteen years and besides other requirements, speech therapy is one of the most important needs of children with speech and mental retardation. I personally raised this issue in different meetings with Secretary and Director Social Welfare but they were silent due to meager financial resources. On the other side, we have a permanent physiotherapist who provide physiotherapies to children, though, the modern and latest equipments for physiotherapies are not available".

As far progress in social welfare is concerned, Ahmed (1993) assets that it can be measured by looking at the production relations of the disable. Providing relief and services to the parents and their children with ID is the primary responsibility of the state. Such measures can prevent families/parents from social and economic agonies. However, due to poor state of social welfare, both parent and children suffer from agonies of ID. The reason of this poor state of services is due to 'social welfare'[21], which is the most neglected sector in Pakistan.

Most of the parents went for displacement, due to poor state of services available for children with ID in Khyber Pakhtunkhwa. A mother said:

> "She [her daughter] needs speech therapy and physiotherapy. We do not have such facilities here in the institute, and thus, I intend to shift to Islamabad for the sake of my child. I have personally raised voice for these facilities at every forum but the government is not interested to provide such facilities. We will shift to Islamabad soon after retirement due to availability of very advanced and equipped institutes in Islamabad."

The same state of services was described by almost all staff members, most importantly, the physiotherapists at different Special Education Complex. For instance, a Physiotherapist shared the same state of services during in an Individual Interview in *HayatabadPeshawar:*

> "The equipments installed in all the institutes are completely useless. We need modern technologies for various therapies of such children".

[21] According to Walter A. Friedlander (1961), Social welfare is the organized system of social services and institutions, designed to aid individuals and groups to attain satisfying standards of life and health, and personal and social relationships that permit them to develop their full capacities and to promote their wellbeing in harmony with the needs of their families and the community (Friedlander, 1961:3).

Another Physiotherapist at the Special Education Complex, Mardan shared during an Individual Interview that:

> "For effective physiotherapies, we need modern equipment of physiotherapies, here we are restricted to vex therapy and muscle relaxer, though, hydro therapy, roll ball therapy, steam therapy etc. are required which are not existent. We rely only on outdated techniques of physiotherapy".

Social welfare is based on two philosophies i.e. welfare values and welfare institutions. The former provides moral and philosophical support, while the latter materializes it. In Pakistan, the philosophy of social welfare is based on charity and philanthropy, which normally is provided by the family. In contrast, the state is following the western model of social welfare in academic and official documents. As a result, there is a clash between the indigenous philosophy of social welfare and provision of social welfare to the needy people.

To guarantee social welfare, people in Khyber Pakhtunkhwa hold firm belief in hard work and wellbeing of oneself and family through personal industry, thrift and saving up for uncertain times. The loss of personal independence is considered shameful. Moreover, family is considered as an institution of social welfare. In a problematic situation, family provides help to the affectee(s). People seek assistance of community and social organizations only when family fails. Similarly, government aid is often seen as the last resort, as was seen in the earthquake of 2005 and flood of 2010, in Khyber Pakhtunkhwa. Moreover, good reputation and enhanced social standing are a few more reasons for engaging in active philanthropy.

7.4.3. Lack of effective and holistic social welfare policy in the province

The poor state of children with ID and their parents are closely associated with the poor welfare systemand lack of effective social welfare policy in the country. The problem of poor welfare system is due to the ignorance of the state machinery from the

guiding principles set by the founder Qauid-e-Azam Muhammad Ali Jinnah for making Pakistan as a true Islamic welfare state.

According to him,

> "Pakistan should not blindly follow Western economic theory and practice, rather develop its own economic system based on true Islamic concept of equality of manhood and social justice and public sector should play a more active role in providing a network of social and public utility services and relief and amenities, especially in underdeveloped areas (Ahmad, 2001: 1134)."

The situation of social welfare is worse in KP as compared to other provinces of Pakistan. The same state of ill-condition of social welfare was shared by a senior official of the directorate in *Peshawar* as:

> "Though, there are 79 institutions in KP, which are providing services to the downtrodden segments of the society such as persons with disabilities, women in crises, orphans children, street children, drug addicts and so many other people in the problems (Interview with Bashir, 2015). There are more than 5000 services delivery staff working on various positions like managers, social case workers etc. However, the sector is not showing any practical outcome as because of the following reasons".

The social welfare policies and strategies that were framed in 1980s were based on the vision and philosophy of the rulers of the country, and were meant to satisfy their political goals rather than to deal with the social problems of the people (Rehmatullah, 2002: 51-52). The very concept of social welfare, that of developing capacities in people to help them to solve their own problems through community development, and people's participation, also the development of self-reliance in communities, was given low priority (Rehmatullah,2002:52).

Though, the UN experts have considered the *Zakat* (Islamic charity) System of Islam as the most innovative form of public assistance, and had recommended that this vast resource be mobilized for social welfare (Rehmatullah, 2002: 227) in the initial stage. However, nothing has been done in streamlining this system for public welfare. After 30 years, its importance was realized by President General *Zia Ul Haq* in 1980,

who formulated *Zakat* and *Ushr* Ordinance 1980. Under this law and system, many destitute people are supported, however, if the Zakat system is properly administered, it can become huge safety net for the poor and the indigent. Though, there is strong criticism against small handouts given to the widows and the needy which only seems to create dependency. Hence, there is need to review the system so that people can become more self-reliant, rather than dependent on small doles (Rehmatullah, 2002: 229).

Similarly, the second cause of failure of social welfare in Pakistan began by adopting imported ideas of social welfare in the form of literature, curriculum and training at academic institutions. The UN had recommended training and education of social work as the only solution for running the social welfare system. However, instead of developing our own curriculum and courses, the country started adopting the imported ideas of western philosophies of social work and social welfare. As a result, such trainings helped the graduates in getting their degrees and jobs, but failed to seed solution for the social problems and provide relief to the poor segment of society.

As far the problems and issues are concerned, some of them are given below:

1. Social Welfare Sector in KP lacks an organizational strategy, consequently, the Human Resource Development (HRD) is the most neglected sector in the province. There are no facilities exclusively available for the development of employee which existed in other provinces of the country as well as in the federal departments.
2. Due to non-availability of HRD facilities in the province, leadership in the same sector has not been developed as a result, no execution of the policies has practically been found, which have promoted a non-professional attitude among the staff of the sector.

3. Moreover, there are limited incentives for promotion among the service delivery and management staff, which have badly affected their performance. They have very limited opportunities for promotion due to non HRD facilities in the sector.

In short, the clash between imported model of social welfare and indigenous philanthropy, the people in need, especially children with intellectual disability, live life without any support except family. Moreover, this dichotomy also causes bad name for the country at international level, as Pakistan has ratified various United Nations conventions on the child rights and persons with disability.

7.4.4. Non-conformity to international commitments regarding child rights

As far as the services and protection of children in general, and children with disabilities in particular, are concerned, Pakistan has international obligations as she is signatory to United Nations Child Rights Convention ,which demands protection of the rights of children without any discrimination. According to the Article 4 of the UN CRC, it is the obligation of the state party to ensure the child's rights as given in convention. Moreover, article 23 of the same convention states that State-party should provide special care and education to the children with disability in society.

For instance, a Physiotherapist shared the same state of services in *Hayatabad Peshawar*:

> "The equipments installed in all the institutes are completely useless. We need modern technologies for various therapies of such children".

This state of services was shared by Head of such institute as key informants during an Individual Interview in *Peshawar:*

> "These institutes/centres provide employment-oriented education to such children which is not beneficial for them as they cannot learn due to limitation in learning, they need daily life skills, how to live an independent life and nothing else".

The same opinion was endorsed by another Senior Official of the Institute in Haripur, *Mardan* and *Nowshera:*

> "We have developed a wrong a concept of special education for children with intellectual disability instead of rehabilitation. They need social skills training rather than education. They cannot learn a page of basics. An official asked me some weeks ago during his visit to this centre that was there any curriculum being followed, I replied that no, these children just followed basics of education".

Moreover, the state party will not only protect them from abuses and neglect at home (article 19) but will also support and assist parents in rearing their children. Moreover, families and parents who belong to less educated and poor background must be guided and supported properly (article 5 CRC).

Furthermore, a parent shared an incidence happened with girl of 16 years old at Punjab who was Intellectually Disabled, *Asiya Maseeh* who was misused for blasphemous act of burning a piece of the Holy Quran. Later on, it was found during court trial that she was innocent due to her mental condition; however, she was misused by a certain group for vacating the place from the Christian minority

Reflecting on this situation, a member in a FDG in Peshawar narrated:

> "We have seen such families of disable who are extremely poor. They use their children for begging in the streets to provide for their family expenses".

Some of the children are forced into child labour owing to the weaker economic position of the entire family. Some children support their families through beggary and other harmful means. This adversely affects the child's personality and bleaks his/her future.

Experiencing the same emotional abuse, a mother of such children started weeping during FGD in Peshawar and narrated her story with extreme sorrow as:

> "My in-laws are usually taunting me for the disability of my child. They say that disability of my child is the result of my wrong doings".

In an interview in Haripur, a paternal uncle of a left-over child with ID who had adopted him as his son, shared the situation in which the child was abandoned:

> "The left over child lives with me and considers me as his father. His parents got separated after the birth of the child with ID and since then, the child lives with me. His mother dwells in Karachi while his father is in Saudi Arabia. My sister extends care to him; however, she is getting married in near future and thereafter his grandmother will look after him".

Besides, UN CRC, Pakistan is also a signatory to the Convention on the Rights of Persons with Disabilities (2007), which emphasizes that "each girl and boy is born free and equal in dignity and rights; therefore, all forms of discrimination affecting children must end." Moreover, "state has to take measures to ensure human rights and fundamental freedom, including equal access to health, education and recreational services, by children with disabilities and children with special needs, to ensure the recognition of their dignity, to promote their self-reliance, and to facilitate their active participation in the community (see Innocent Digest-13 by UNICEF)."

When a Social Case Worker was contacted about the state of gender disparity in education of female children with ID, he reflected and shared his experiences in Peshawar:

> ".....Parents hesitate to send their disable child to any special education school, especially girls".

As for the gender preference for special education is concerned, it was observed in this study that the prevalent culture normally determined such priority. Generally, in Pakhtun society, male child is given preference over female child as far education in general and special education, in particular is concerned. Parents invest in male child with the intension that he will be earning for the family in future. Female child, on the other hand, is perceived as non-productive economically for the family and ,consider her

a guest in families, as she has ultimately to marry As a result, parents prefers male child over a female child. As for special education is concerned, a grandmother shared her experiences in Peshawar and presented justification for the gender inequality:

> "My two grand-children suffered from such disability. One is male child while the other is female. As far the education of the children was concerned, the family can afford their education, however, we decided to allow male child to attend special education school while female child was kept at home as she cannot protect herself from any abuses".

It was found in the study that female children were discriminated on the basis of femininity and disability, and were thought as non-productive entities of society.

The inclusion of children and person with disability into mainstream society is possible through advocacy and voicing for the rights of this segment of society.

The disability movement was initiated by persons with physical disabilities in the province as the orthopedically challenged person could advocate their rights personally at all forum. Consequently, they had highlighted their special needs and problems effectively both at national and international level. Moreover, their cause was supported by the polio-eradication movements in the country, which had generated huge funds. Hence, the special education centres were equipped with resources needed for persons who were physically challenged only. Though, the occurrence and existence of crippled disabilities caused by polio have completely been controlled in the country, and rare cases of polio affected children had been attended by such centres in the province.

Owing to the non-existence of required rehabilitative services for such people in the province, they and their parents lived with agonies. Such children and their parents constituted a voiceless and helpless segment of society. Like physically disable people, such children cannot advocate their rights due to intellectual limitation. Furthermore, their parents are paralyzed by the socio-cultural and economic constraints. Such parents either hide such limitations due to fear of stigma as people associated occurrence with

the sins and bad actions of the parents in Khyber Pakhtunkhwa. As a result, they restrict them to home.

In short, this chapter discussed that prior to 1970s, the ''medical or personal tragedy thoughts were prevalent, resultantly, disability was seen as a physical deficiency. It was considered to be rooted within the individual. Logical end of this approach was that the disable cannot work in the major aspects of life (Oliver, 1990: 10). The rights of PWDs movement as a social movement was remarkable as it provided an active voice to a passive segment of the society (Campbell & Oliver, 1996).

The International Labor Organization (ILO) estimates that disable person can contribute at least 3-7% of the global GDP. But we are losing this contribution (World Bank, 2000). Furthermore, disability is often defined in economic perspective unfavorable situation that cause inability to work. According to Charlton (2006), "people with disability have been socially oppressed which made them less economically productive members of society, and viewed them as part of the underclass due to their lack of participation in wage labor (Charlton, 2006:218)."

Similarly, mothers of disable children always keep complex, and marginal position against such discrimination (Voysey, 1975). This marginalized status of mother is an issue of non-disable mothers' status in disability studies (Voysey, 1975; Birenbaum, 1992; Veck, 2002).

7.4.5. Special Education Centres were overwhelmed by multiple problems

Children with intellectual disability constitute a substantial number of population in Khyber Pakhtunkhwa. Hence, no holistic programs for their rehabilitation existed in the province. The only hope for such children and their parents was the inadequate and urban-based special education centers in the selected districts of the province. These centers are encountered with scarcity of trained staff and modern assistive technologies

required for rehabilitation of such children. These centers were established in 80's in the era of General Zia Ul Haq as his own daughter "Zain" had got disability. That was considered as the golden era in the field of special education and social welfare. Thereafter, no result-oriented services and institutes were established in the country.

There were many reasons for such non-provision, which was shared by different officials. For instance, the lack of such services, was shared by a Head of the Institute during in*Nowshehra*:

> "We do not have trained and professional vocational trainers in the institutes. Moreover, initially there was a trainer, but, he was not expert in his field as result his role was not very effective. As children with ID cannot learn through simple ways rather needs more sophisticated and modern techniques".

The situation of children with Intellectual Disability in Pakistan is in doldrums. Institutional factors can influence the rehabilitation of children with ID (Carrier, 1986b and Barton, 1981). In addition, schools' test can also influence rehabilitation of IDs (Ysseldyke, 2001). According to the latest estimates by Autism Resource Centre (ARC), there are 350,000 Autistic children in Pakistan, which mean 1 out of 66 children is autistic (Haider, 2015). In Khyber Pakhtunkhwa too, the magnitude of such disabilities among children is on rise. According to a survey report, the most common types of diseases and disabilities identified among children in the province are fits, mental retardedness and difficulty in speaking (Govt. of Khyber Pakhtunkhwa, 211:12).

As far the high occurrence of ID among children is concerned, the situation was narrated by a Head of the Special Education School/Centre for Physically & Mentally Retarded Children, *Bashir Abad:*

> "The number of children with intellectual disability is increasing day by day as compared to polio affected children. We provide physiotherapy services from 10 to 15 children as out-door-patient (OPD) per week and out of which 90 to 95 % children suffer from Mental Retardation"

Similar responses and feedbacks were received from the in-charge and physiotherapists of the special education schools at *Hayatabad, Haripur* and *Sheikh Multan, Mardan.* For example, the physiotherapist from *Mardan and Peshawar* disclosed:

> "We provide services to children having disability of all kind. Presently, 83 children with physical disability are enrolled while more than 250 children in the center having Mental Retardation which constitutes 95 %

It was shared by almost all officials of the special education institutions that prevalence of children with intellectual disability is increasing as compared to other disabilities. However, the second most prevalent disability found in the study was hearing impairment among the children.

It is generally agreed upon that the adequate provision of rehabilitative services for children with intellectual disability depends on the knowledge of the number of children who need such services (Allen-Ile & Grol, 1997). In Pakistan, the exact number of intellectually disable is not known due to the lack of official census on regular basis.

In reality, the Special Education School/Institutes working for the rehabilitation of such children were unable to rehabilitate or train these children with ID due to its poor state of services. Moreover, these institutes were overwhelmed by multiple problems ranging from scarcity of funds, trained staff, infrastructure, transportation and modern equipments etc.

A manger of the Institute for Children with Mentally and Physically Retarded Children, *Nowshehra* shared her views about the poor state of equipments as:

> "All equipments and assistive devices in the Institute are out of order or useless fortherapies, as these were installed some 30 years ago ...I have raised this issue in different meetings with high-ups of the Directorate, but no action has been taken so far. Same is the case of other institutes working for such children in the province".

Almost all the officials mentioned the need for the latest technology and devices to cater the needs of children with disability. For example, an official said:

> "Though we provide physiotherapy services to children with all types of disabilities, however, some of the available equipments are out of order. We feel that there is a need for other equipments and services such as speech therapy, music therapy, social skill therapy, which are currently not available at our centre".

It was found that equipments and assistive devices available in the centers were either out dated or non-functional. These disabilities and their requirements have changed, but this change is not reflected in the institutes in terms of available equipments. This state of affairs is affecting the treatment and rehabilitation of children with disabilities. Along with modern equipments, the kinds of services provided at the centres are also outdated, as there is a need for more services, such as speech therapy.

However, it was observed that parents/family members were not happy over the poor performance of such institutes, as they were serving a 'time-passing' policy for both staff and parents. Moreover, such trend was found in poor families embedded in joint family structures. However, those parents who were more ambitious about the growth and development of their children with ID, had mobilized all their potential and resources for this cause. Hence, most of them have adopted displacement and migration for providing special care and education in special education school/center for their children's rehabilitation in the society.

For instance, parents shared their opinionsabout the state of services being provided by the institutes as:

> "I am not satisfied with the attitude of the staff and services of the institute as I have not seen any improvement in my son. My son learnt abusive language in the school"

Similarly, experiences were shared by other parents as well:

> "Though, I am not satisfied from the attitude of the staff members and the development of my child in the school/center since his enrollment, however, it provided me an opportunity to fulfill family and other social activities of the family and community".

Furthermore, there were private institutes in the capital of the country (i.e. Islamabad) which were highly equipped with technical and human resource and played important role in training and rehabilitation of such children. However, those families who are extremely poor and unable to bear the expenses of treatment of these children ignore them. Such ignorance, mostly observed in the form of children missing reports in different daily newspapers, which could be used by criminal gangster for anti-social purposes like organs transplantation and begging. Similarly, some parents are usually compelled to seek loan from relatives for bearing their expenses, or mostly force their normal and defected children towards child labor or child beggary. Most poor families use the disabilities of such children for earning purpose and push them in different market and bazars for begging purposes.

Owing to the non-existence of rehabilitative services in the province, such children and their parents are passing through agonies. Such children and their parents are voiceless entities, as they cannot advocate their rights due to intellectual limitation, and their parents are paralyzed by the socio-cultural and economic constraints. Parents having children with intellectual disabilities hide such limitation due to the fear of stigma on their deeds. Society generally associate the birth of such children with sins and bad actions of the parents in Khyber Pakhtunkhwa. As a result, such children are mostly restricted to home. However, the parents who approached special education centres intend to provide breathing space for managing household activities as they require full time care, consequently, parents fail to provide care to them and continuously face fear of mislay of their children.

7.5. Over-emphasis on Polio Eradication has overshadowed the Problem of Intellectual disability in the province

No doubt, Pakistan is facing international pressure for eradication of polio, but this pressure has completely overshadowed the problem of intellectual disability. Resultantly, there is no policy, services, instruments and trained professional at any centres of the province. For example speech therapies were found as inevitable need for such children but due to polio-driven policy, centers' are equipped with equipment's for physiotherapies.

Moreover, it has vital impact on the family as well as on society. Billions are spent annually for the prevention of polio as compared to intellectual disability in Pakistan. Since 1988, over 2.5 billion have been immunized against polio and more than 200 countries and 20 million volunteers, backed by an international investment of over US$ 10 billion (PILDAT, 2012:10).

The prevalence of Intellectual Disability among children in Pakistan is higher than many other types of disabilities. According to the Census Report of 1998, 14 % children suffering from ID in Pakistan, while 4% children were suffering from intellectual disability in Khyber Pakhtunkhwa province (Government Report, KP, 2011).

On the other side, 25 cases of polio were reported from January to July 2015 in Pakistan, out of which only 13 cases were reported in Khyber Pakhtunkhwa (WHO, KPK, 2015). Moreover, it will be completely eradicated by the end of 2015 due to extensive vaccination campaign (Interview with Official of WHO, 2015).

This was also stated by renowned pediatrician and Deputy Speaker of the Provincial Assembly, KP during her speech, 'no doubt eradication of polio is important; unfortunately, over the last 15 years, we have overlooked the routine immunization. Mothers also believing that by receiving the polio vaccine, routine immunization is completed"(Roghani, 2016).

On the other side, it was found that intellectual disability is more prevalent and nothing has been done for its prevention. For instance, a Social Case Worker shared his practical experiences during in an Individual Interview in Peshawar:

> "The situation of intellectual disability (previously known as mental retardation) is on rise in Khyber Pakhtunkhwa, but unfortunately nothing has been done for the prevention and rehabilitation of children with ID. The Institutes have no such facilities for the treatment & rehabilitation, however, all the institutes in the province are focusing on physical disability" (Interview with a Social Case Worker, 2014)".

The same comparison of high prevalence of intellectual disability as compared to physical disability caused by polio, was shared by the Head of the Centre for Physically & Mentally Retarded Children, *Bashir Abad, Peshawar* (2014):

> "The number of children with intellectual disability is increasing day by day as compared to polio affected children from the past years. We provide physiotherapy services (10 to 15) children per week as an OPD and out of which 90 to 95 % children suffer from Intellectual disability/Mental Retardation".

She further added that:

> "We are rarely receiving/attending physically or polio affected children as it has completely been overcame due to extensive vaccinations campaigns".

Similarly, the same situation was observed in the other three districts of the province. According to the officials of the Special Education Schools/Centre at *Hayatabad,Haripur* and *Sheikh Multan, Mardan* (2015):

> "We provide services to children with disabilities, however, mental retardation/intellectual disability constitute 95% as compared to physical disability".

Now, there is a need to focus on the prevention of intellectual disability in Pakistan. As a huge number of children with ID and their families are suffering due to lack of societal attention in Pakistan. People are blind about its prevalence due to lack of

official census in the country since 1998. Resultantly, there is no accurate data of such disability, however, on ground, its prevalence is higher than polio.

As far the causes of ID are concerned, besides genetic causes, most of its causes are associated with social factors like endogamous marriages, negligence in Rh screening of couples and cultural constraints for mothers in pre-natal and natal care (delivery at home, lack of vaccinations) and extreme poverty.

Summary

The care for child with special needs is a collective concern. Family and social welfare institutions provide social services to the children with ID depending upon their social and political structure. In more advanced societies, welfare services for IDs are provided by state institutions and the families. However, in more traditional societies Khyber Pakhtunkhwa, it is the job of the family to provide for social welfare needs of the children. Social welfare institutions including special education schools have failed to provide relief to the parents having children with ID.

Social welfare in Pakistan is in-between of charity-oriented activity and professional activity which benefits only orphans, old, and destitute women. The 1973 constitution of Pakistan held Pakistan as "Islamic Welfare State" but on the ground, there is no safety-net for the welfare of poor and needy segments of society. The role of state in welfare provision is least effective, consequently, such activity is performed by family, while its benefits are restricted to short-term "help" rather than 'enabling' role. Similarly, social welfare in Khyber Pakhtunkhwa is growing like other provinces, however, it has not shown any result oriented progress. The poor state of children with ID and their parents are closely associated with the poor welfare system and lack of effective social welfare policy in the country. Though, Pakistan is signatory to the UN conventions regarding child rights, even then, no progress has been shown in this regard.

The Special Education School/Institutes working for the rehabilitation of such children were unable to rehabilitate or train these children with ID due to its poor state of services. Moreover, these institutes were overwhelmed by multiples problems ranging from scarcity of funds, trained staff, infrastructure, transportation and modern equipments.

CHAPTER08 CONCLUSION

This study primarily aimed to explore the effects of child with intellectual disability on families in Khyber Pakhtunkhwa. Theoretically, ID is a type of disability which has multifaceted effects on families. However, the intensity of such effects varied from family to family owing to numerous socio-economic, political and cultural dynamics. For instance, it was found from the primary data presented in chapter 5 and 6, that the intensity of such effects was higher on nuclear families as compared to joint families, due to limited support of family members. The families are being transformed from joint to nuclear due to the phenomena of urbanization. Hence, the loss of indigenous support system in such families exposed them to undesirable effects due to the nuclearization of families where the social support is less than joint families. Family members such as in-laws/grandparents, brother-in-laws/uncles, cousins etc. found in joint families usually extend social, physical, financial and psychological support to affected parents, especially to mothers in primary care of such children and other household activities in such families. Nuclear families which consist of only parents and their unmarried children have limited human and financial resources. Such are unable to extend all the required support for their children with ID. As a result, indifferent and negative attitude towards child with ID disturbs the social fabrics of families and leads to social, psychological and economic problems such as role conflicts, strain relation between parent and non-disable children and between spouses, social exclusion for primary care givers, and stress of over-burden on mothers which ultimately cause family disorganization or displacement.

Within the family, mothers were found to be effected even more due to her role as primary-care-giver compared to father. In other words, mothers, as primary care giver, and manager of household chores, were on the frontline of adversaries. Though,

their status and role is mostly unpaid job and unrecognized. Furthermore, the close association of mother with such children mostly causes courtesy stigma for them which results in strain relation with non-disable children and other family members due to least attention for them. Such tension sometime affects relation with spouse as well, which causes rejection and social breakdown in the form of divorce. Such adversaries for women, as discussed in chapter 7, exist owing to the patriarchal structure of society where male enjoys superior position both within as well as outside the family due to power of decision making and possession of financial resources. Men, in the form of husband and father hold superior status in society, hence, he is almost exempted from care-giving roles and other physical responsibilities.

However, the extra financial burden which accompanies a child with ID is mostly born by father and other male members of the family. As far the financial burden on families is concerned, it is due to special needs of such children such as frequent medical assistance as compared to non-disable children due to weak immune system, hence, required regular medical checkups and various therapies required for such children. Therefore, the father as bread earner has to bear such burden. However, such financial burden is felt more in nuclear families as compared to joint families due to limited sources of income in nuclear families. In joint families, on the other hand, the primary giver receives not only logistic support but financial assistance as well due to multiple sources of income.

Financial weakness and low literacy ratio among the parents inclined them towards superstition induced behavior and practices. Most of the parents associated the cause of ID of their children with some superstition such as bad eyes of the jealous relatives and influence of ghosts, consequently, they followed similar ways of treatment like taking their disable children to shrines of saints, religious people for spelling holly

words or other similarly practices. Such practices badly affected the control and recovery of ID which could be controlled by early detection and therapies.

The birth of the child with ID coupled with negative attitude and patriarchal features of society exert psycho-social and economic effects on families. Such effects may be curtailed by certain actions in society. It was found in the study that the government takes least interest in taking care of such children. Due to the absence of an effective policy and institutional support, families have to bear the burden of care and training of their disable children Moreover, it was found that there were not only limited institutional services for such children in the province but those few available institutional services were overly concentrated in urban areas only. Family in rural areas who were unable to avail urban based services were facing even more problems. Even the urban based institutions were not up to the mark; they were extremely poor in terms of services and were unable to provide effective training and counseling services to such children or their parents.

The main cause of failure of these social welfare institutions is the transplantation of an imported model of social welfare into Pakistani context. Consequently, despite the huge structure of social welfare in the province with almost 5000 staff more than 500 million rupees as Annual Development Budget (ADB),no impact-oriented results neither for the children nor for the families are visible.

Keeping in view the adverse effects of child with ID, this study suggests the following measures which can minimize the adverse and disastrous effects on families.

An exclusive survey and research study or Census should be conducted by the government for identifying the number of children with ID in all districts of the province to know the frequency of such children. Moreover, experts in psychology, psychiatry, medicine and other social scientists should be involved in probing the cause of such

disabilities, hence, a preventive strategy should be devised like polio vaccination process for overcoming the adverse effects of such disabilities on society.

An operational and exclusive social policy for such children and their families may reduce such manifold challenges. Such exclusive policy may contain various social, psychological, medical, rehabilitative strategies for children with ID for making them independent citizens of society. Such strategies, can be implemented in the form of multifaceted program through community-based, familial-based as well as institutional-based programs, for the care of such children and their families. Such program must contain social training and counseling services to family members which may low down the negative effects on families.

Revival of the indigenous system of social welfare and social support based on charities and *Zakat* is needed for the support of children with ID and their families. For strengthening and making the institutions of charities and *Zakat* system transparent, the system should be associated with prominent personalities or philanthropists of countries such as *Abdus Sathar Khan Edhi* (a prominent philanthropist of Pakistan who runs *Edhi* Foundation based in Karachi), or Imran Khan (former cricket star, politician and renowned social worker and founder of *Shoukat Khanum* Memorial Cancer Hospital in Pakistan) for receiving maximum zakat money. Currently, *Zakat* money is channelized through *Baitul Mall* (Arabic word mean house of money)a Government institution runs through *zakat* money for the welfare of destitute people in Pakistan), however, due to lack of people's trust in the system, the contribution to the fund is low. Moreover, it has no transparent strategy for distribution of zakat money. Voluntary contribution of public in the form of *zakat* must be enhanced by involving such personalities for giving them a sense of trust. Moreover, informal charities should also be channelized and received

effectively by mobilizing such public-oriented philanthropists to maximize the financial strength of the directorate of social welfare and special education.

Social skills and counseling training have to be organized for the parents and primary care givers at community level and equipped them with skill and training to cope with ID of such children. It will lesson burden on the institutions and will benefit large number families in overcoming agonies caused by lack of information and skills.

Families who have children with ID must be given special preference in different social welfare programs such *Benazir* Income Program in Pakistan wherein special allowances on the name of such children should be given to mothers having such children so that they may bear the expenses of such children effectively. Moreover, education and health cost of such children should be waived off by the government.

8.1. Theoretical implications of the study

Children with ID have wide-ranging effects on families (Albin and Mank, 1997; Andrews and Whithey, 1976; Campbell, *et. al.*, 1976). The existence of institutional care greatly helps in minimizing such effects (Jackson and Mupedziswa, 1988 and Chan, 1997). The empirical finding of this study, however, reveals that a mere presence of welfare institution is not enough. In Pakistan, families continue to face the effects mainly because the welfare institutions are not functional in the real sense of the term. According to Carpenter and Herbert, (1995: 8) institutional intervention can mitigate the miseries of families. However, institutional services matter when they are fully developed and equipped with facilities and latest technologies, and expert and skilled social workers. The empirical finding of this study found that families were adversely affected due to lack of effective role of the institutions.

Previous studies (Kermanshah, *et. al.*, 2008; Marder, 2008; Miles, 1983; Mitra, Posarac, Vick, 2012; Monk and Wee, 2009; Shahzadi, 1992; Stein, 1981; Tareen *et.*

al.,1982; Thomas and Thomas, 2002) have revealed the effects of ID on family functions. However, it has never been projected that such effects varies from family to family in term of structure. The empirical finding of this study exposes that nuclear families are affected more than joint families. In other societies, especially in developed societies, families mostly exist in nuclear form (Carpenter, 1996), hence, the impact of children with ID were generalized for all families which is contrary to the ground reality. Similarly, family values and lifestyles in some cultural groups, serve as a source of strength when coping with a child with special needs (Miles, 1983; Ceylan and Aral, 2007). The phenomenological and interpretive approach of this study exposes that socio-economic and cultural reality varies, hence, the effects may also vary from family to family. The adverse implication, as referred above, on joint families is less due to social, financial, logistic and care-giving support. Furthermore, the existence of such support also overcomes the poor outcome of institutions in provision of services to such children and families.

Other studies (Reeta, *et. al.,* 1998; Moudgil et. al., 1985) highlight the role of parents and sibling in primary care giving (Carpenter, 2006). However, the role of other family members such as mother-in-law, father-in-law, sister-in-law and other close relatives has never been highlighted by such studies. This study finds that positive and supportive role of such family members who prevent affected families from displacement and disorganization. Such secondary and tertiary kins provide social support to the affected parents which is normally extended by institutions for their counseling and psychotherapy. Hence, this support can be used as social capital for less developed societies such as Pakistan where institutions cannot cater to the needs of both children and their parents.

Like variation in effects of ID on family structure, such effects also vary from gender to gender, for instance, mothers suffered more than fathers. Studies carried out in developed societies (Cohen, 2008; Mita*et. al.*, 2005) revealed that both mothers and fathers suffered the same, however, the present study found variation in effects on family members according to gender. Societies where gender role is determined by patriarchy, their status and roles carry different challenges for men and women (see Memela, 2005; Walsh, 2001). Family roles in Pakistan is based on patriarchal features, hence, women are responsible for domestic roles while men are responsible for affairs outside the families (Shah, 1989 and Naz, *et. al.*, 2011). Consequently, the birth of the child with ID exerts extra burden on the women as primary care giver in addition to other family roles. In such situation, mothers also face emotional and verbal abuse in the form of taunt from society. Moreover, mother also face divorce and stigma due to her weak position in the family.

Normal children are also affected due to the presence of child with ID (Alper *et. al.*, 1994; Ishizaki, *et. al.*, 2005; Stoneman, 2005).Other studies have restricted such affects to strain relations of normal children with mother and the child with ID (Eget, 2009; Cox, *et. al.*, 2010) while this study reveals that health and education of the normal children, especially the female siblings are adversely effected. Owing to extra needs of the child with ID, the quality of food and education of normal children is badly affected. Most importantly, the female siblings normally sacrifice their education as she has to extend support to her mother in dealing with such children, hence, she is normally taken out of school.

This study revealed that apart from the poor infrastructure of existing institutions, other factors such as lack of indigenous and culturally compatible system of social welfare as equally responsible for ineffectiveness of the institutions for dealing

with children having ID and their families. Pakistan developed its social welfare system with the support of United Nations in 1952 (Ullah, 2005), since then, the system have not relieved the miseries of poor segments in general and disable population in particular due to its incompatibility with social structure of Pakistan. Hence, an indigenous and culturally compatible system of social welfare system could remedy the miseries of children and their parents in a traditional society like Pakistan.

8.2. Areas for the future prospects

A number of studies (such as Sletved, 1981; Khatoon, 2004; Suliman, 2005; Mach, 1988) have been conducted in detail regarding disabilities in Pakistan, however, none of them is comprehensive enough to study all the concerned and relevant aspects of the issue of intellectual disability, including the special education and social welfare in Pakistan. It is worth mentioning here that in Pakistan, *Punjab* province has comparatively an effective and developed system of social welfare and special education structure in facilitating and serving children with ID. This study would have been more effective if a comparative study of *Punjab* province and Khyber Pakhtunkhwa province had been conducted by studying the institutional structure, role and performance and their effectiveness in remediating the problem of children with ID and their parents. This study, if carried out in a comparative way, would definitely create good reasons, dynamics and a comprehensive understanding of how institutional role can make the difference in the field of disability, social welfare and special education in Pakistan.

This study has tried its best to have in-depth analysis of the issue, however, effective policy is based on effective informed and inclusive study, hence, a study needs to be conducted to develop social welfare and special education structure of the developed countries such as United States of America and United Kingdom etc. with regard to their performance and helping out the children with ID. Hence, it's a good

work for the future researchers that why the institutional network or institutional functions in the developed countries have been effective in helping the ID people in rehabilitating them and minimizing the agonies of their families. Hence, a comparative analysis must be made between the institutional performance of the developed countries and Pakistan, hence, such study will help out the country in formulating an effective policy for such children with ID and their parents.

In addition to it, this study has explored the effects of child with ID on both men and women, however, it was found that women are the worst affectees of such condition of their children, hence, it was realized in the mid of the study that an in-depth and an exclusive studies need to be carried out on exploring the mothers having children with ID for further exploring their life experiences and the problems they encountered due to such children. Such a study will enable society to take special care of such mother in terms of policies and services to them. Moreover, those social factors which are negatively affecting their personality, social life, health and smooth functioning in society must be addressed through various actions.

Similarly, another study need to be carried out, highlighting the importance of ID children in society, as society gives facilities, benefits and entitlement to people and children with physical disabilities, on the other hand, children and people having ID have completely been ignored. They are "the special of the special people", hence, such study may try to surface the reasons of such negligence and help out such children and their families to cope with such challenges effectively.

Similarly, another study needs to be conducted to know the comparative analysis of the effects of physically, visually or hearing challenged children and children with ID on the families. It may reflect t whether disability of any type has similar impact on parents and families, or it vary from disability to disability.

Summary

The intensity of effects was higher on nuclear families as compared to joint families due to limited support of family members. The families were transformed from joint families to nuclear families due to the phenomena of urbanization, hence, the loss of indigenous support system in such families exposed them to undesirable effects due to the nuclearization of families where the social support is less than joint families which exerts adverse effects such as role conflicts, strain relation between parent and non-disable children and between spouses, cause social exclusion for primary care givers, stress of over-burden on mothers which ultimately cause family disorganization or displacement. Within the family, mothers were affected more due to sole primary-care-giver as compared to father.

Such adverse effects were also associated with the lack of interest of the Government in taking care of such children, the mitigation role of the institution is less, hence, families bear the burden of care and training. Moreover,the absence of an effective policy and institutional support throws overall burden on families.

- Hence, an operational and exclusive social policy for such children and their families may reduce such manifold challenges.
- Revival of the indigenous system of social welfare and social support based on charities and *Zakat* is needed for the support of such children with ID and their families. For strengthening and making the institutions of charities and *Zakat* system[22] transparent, the system should be associated with prominent personalities or philanthropists of countries.

- An exclusive survey and research study or Census should be conducted by the government for identifying the number of children with ID in all districts of the province to know the frequency of such children.
- social skills and counseling training for the parents have to be organized for the parents and primary care givers at community level and equipped them with skill and training to cope with ID of such children, hence, it will lessen burden on the institutions and will benefit large number of families in overcoming agonies caused by lack of information and skills.
- Families who have children with ID must be given special preference in different social welfare programs such *Benazir* Income Program in Pakistan wherein special allowances in the name of such children should be given to mothers having such children so, that they may bear the expenses of such children effectively.

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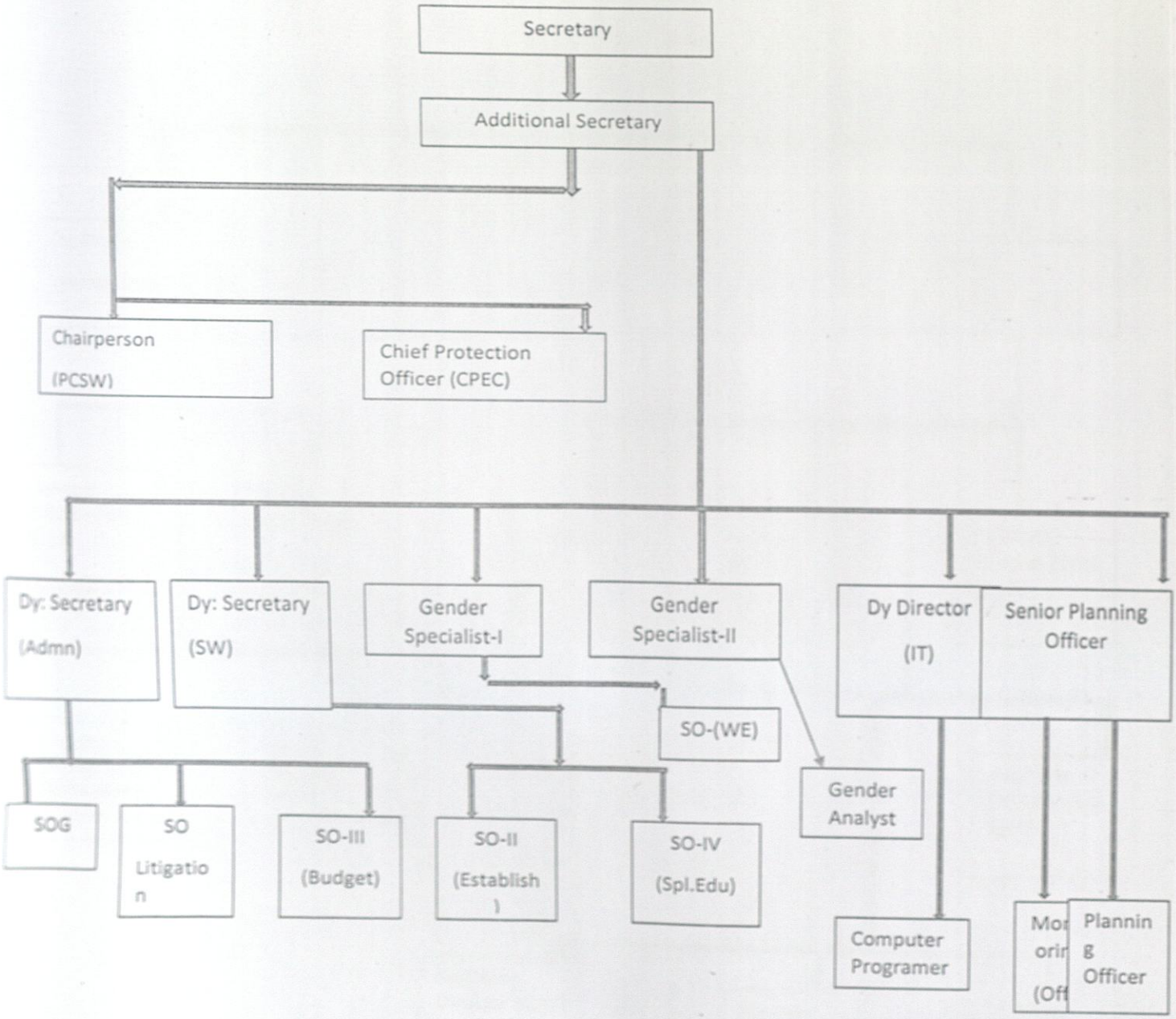
Annexure I:

Figure 3: Social Welfare Organogram (SECRETARIATE LEVEL)



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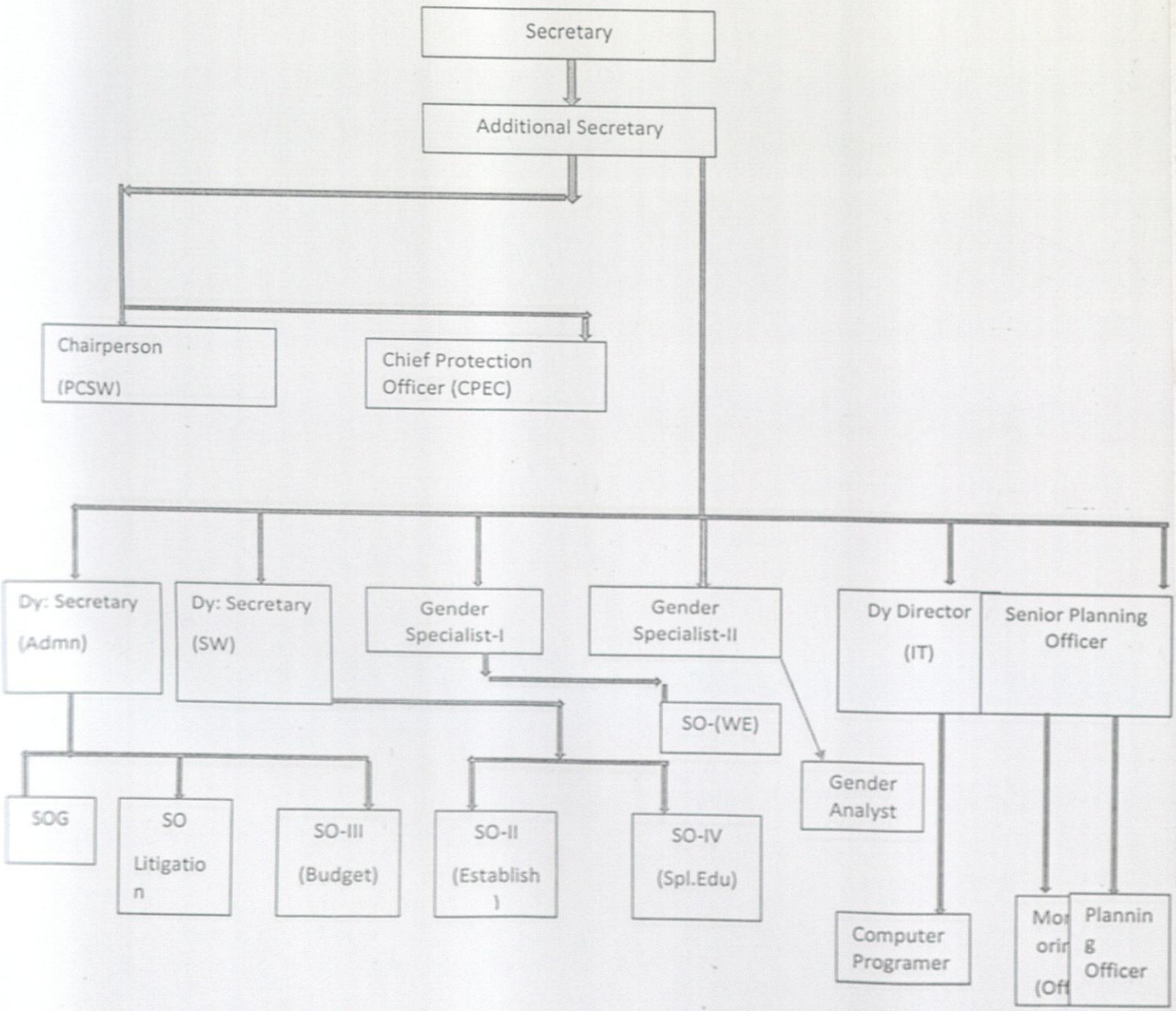
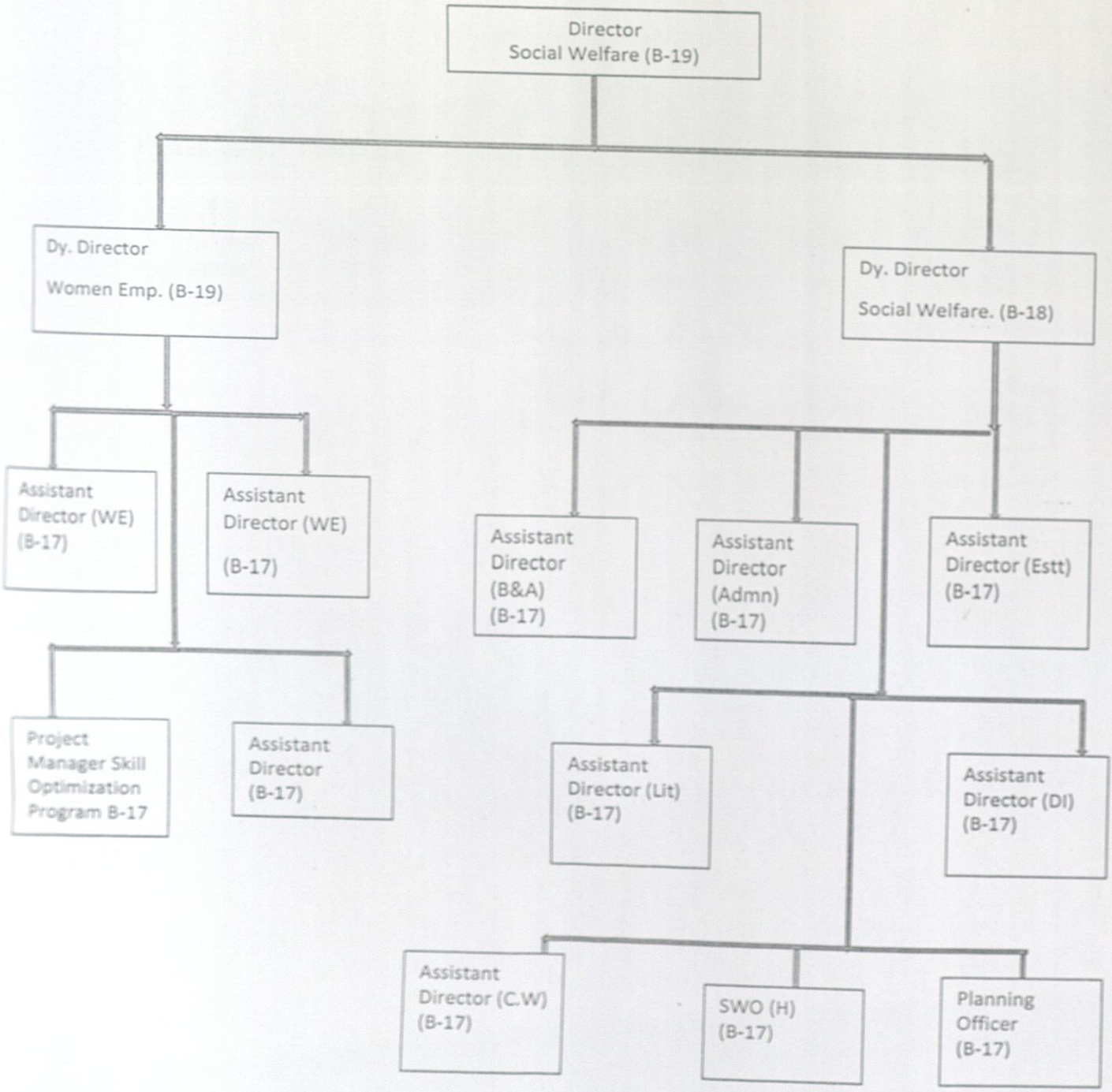
Annexure I:

Figure 3: Social Welfare Organogram (SECRETARIATE LEVEL)



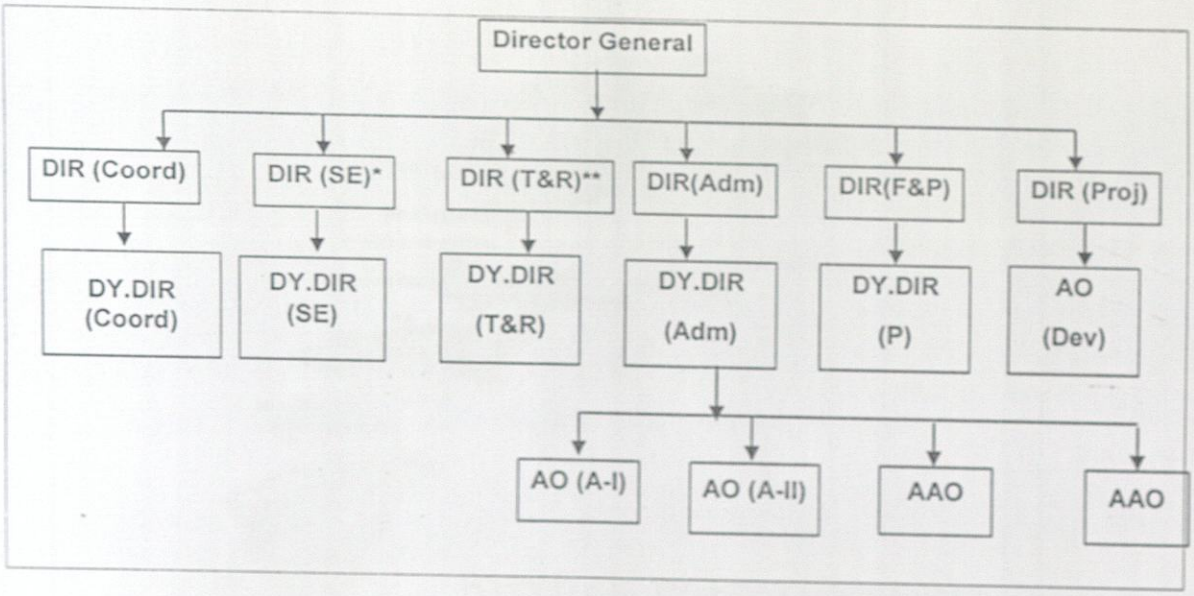
Annexure: II

Figure 4: Organizational Chart of Directorate of Social Welfare, Special Education & Women Development, Khyber Pakhtunkhwa



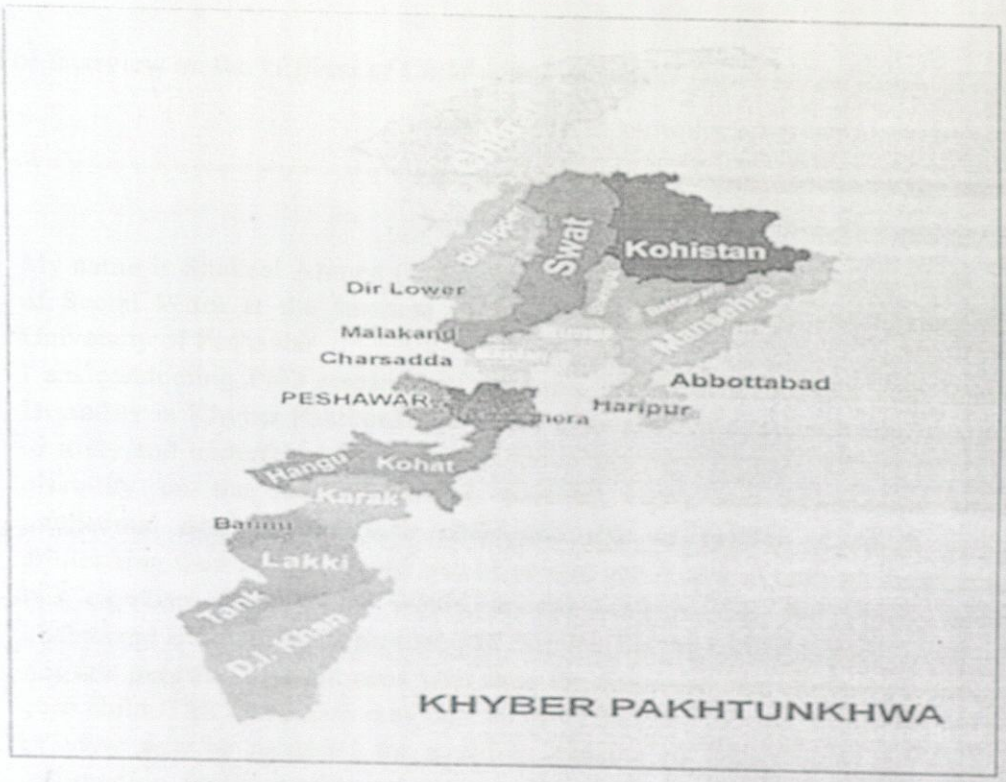
Annexure III

Figure 5: Organogram of Directorate General of Special Education, Islamabad



Annexure: IV

Figure 6: Map Showing Districts of Khyber Pakhtunkhwa



Annexure: V

Informed Consent of parents

For Interview on the "*Effects of Child with Intellectual Disability on family in Khyber Pakhtunkhwa*"

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1. My name is Shakeel Ahmed (Interviewer), enrolled as a PhD scholar in the subject of Social Work at the Institute of Social Work, Sociology and Gender Studies, University of Peshawar.
2. I am conducting PhD research on the topic of "Effects of Child with Intellectual Disability in Khyber Pakhtunkhwa". This is an academic research and its purpose is to study and understand the socio-economic and psychological effects of child with disability on the family. Further, parents' views and experiences about the intellectual disability of their child and role of special education centres in minimizing their burden would also be sought out. You will have no direct benefit of this exercise; however, it would benefit academicians and policy makers to understand and realize the problems of families having such children.
3. For this purpose, I would need your time for discussing the intellectual disability of your child. This discussion may take 60 to 90 minutes. During discussion, your point of view will be recorded for avoiding missing of information? However, your information, family profile and names will be kept confidential.
4. Your participation will be entirely voluntary and there would be no financial liabilities from any side.
5. During discussion, you can stop it at any time, further, if you could not understand any question, you can ask for clarification and explanation.
6. A photocopy of this consent form will be provided to you after signature for your record and future correspondence if required.

==========

I, _____ (Interviewee), resident of

_____

_ hereby agree and give information to Mr. Shakeel Ahmed about the intellectual disability of my son/daughter on voluntary basis. I do not expect any financial reward for this exercise. I will get photocopy of this consent form for my personal record.

Interviewer Signature:_____ Interviewee signature: _____

Cell # 03339111085

Date: _____ Date: _____

Annexure: VI

Check list for Interviews on "Effects of Child with Intellectual Disability on family in Khyber Pakhtunkhwa"

Objectives:

- To explore and interpret the parents views, reactions, perceptions and experiences about their children with intellectual disability.
- To explore the socio-economic and psychological effects on families having child with intellectual disability.
- To know about the efficacy of the facilities extended by the government to mitigate families' sufferings from the problems

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Profile of Respondent:

1. Date of Interview: _____
2. Interview starting time: _____ Interview ending time: _____
3. Name of Respondent (optional) _____
4. Address of Respondents: _____
5. _____
6. Contact Number (Optional) _____
7. Relation with the Child: Mother ( ) Father ( )
8. Type of marriage: Endogamous ( ) Exogamous ( )
9. If endogamous, relation with spouse:
10. _____
11. Type of family: Nuclear: ( ) Joint family: ( )
    _____
12. Education: Literate ( ) Illiterate ( )
13. Level of education: _____
14. Employment status: Government servant ( ) Private employment ( ) self-employed ( )
15. Monthly income: _____
16. Total dependant: _____

17. Total number of child (ren) with ID: _____

18. Age of the CID: _____

19. Gender of CID: _____

20. Birth order of CID: _____

21. Type of I.D: _____

22. Number of other children: _____

23. Is this first child in your family with such disability? Yes ( ) No ( )

24. If No, give detail of other such disabilities in your family. _____

_____

OBJECTIVE: 1 (PARENTS VIEWS, REACTIONS, PERCEPTIONS AND EXPERIENCES)

1. Will you please explain your understanding of Intellectual Disability?

   _____

   _____

2. According to your opinion, what may be the causes of such problems?

   _____

3. What is the prevalence ratio of this in your family?

   _____

4. How intellectual disability of children explain/worded/phrase in your community?

   _____

5. When did you first time feel that the child had intellectual disability?

   _____

6. Have you shared your observations with someone? Yes ( ) No ( )

7. If no,

   why _____

8. If yes, with whom:

   _____

9. What was his/her reply in this regard?

   _____

10. Can you share the symptoms indicating such abnormalities?

_____

11. Have you taken him/her to health practitioner for check-up?

_____

_____

If not, what was the reason:

_____

_____

If yes, what was his/her area of specialization?

Physician ( ) Psychologist ( ) Psychiatrist ( ) Neurologist ( ) Para-medic ( )

Don't knows ( )

12. Have you ever taken him/her to saint's shrine for recovery purposes?

_____

_____

What was the age of the child at the time of diagnosis?

_____

13. How would you describe your reaction when you first learnt about your child's disability?

_____

_____

14. Can you describe the reaction of other family members to the discourse of I.D?

_____

_____

OBJECTIVE NO. 2 (SOCIO-ECONOMIC & PSYCHOLOGICAL EFFECTS OF CHILD HAVING INTELLECTUAL DISABILITY ON FAMILY)

15. Has the child with Intellectual disability exerted any extra burden on the family members?

If yes, can you describe the nature and type of burden?

a) ( ) Social exclusion, please elaborate

b) ( ) Home management burden, please elaborate

c) ( ) Problems in look after of other children, please elaborate

d) ( ) Economic burden, please elaborate

e) ( ) Mobility problems, please elaborate

f) ( ) Emotional burden, please elaborate

16. Has the extra care of IDC affected your relation with other children?

_____

17. How people respond to you on the disability of your child?

_____

18. Have you felt headache after the appearance of disability of your child?

_____

19. Have you found any emotional disturbances in your personality? (Anger, sorrow, weeping etc)

_____

20. Have you felt disappointment/hopelessness after this problem?

_____

21. Has it affected your marital relation with your spouse?

_____

22. Have you ever felt guilt due to this problem?

_____

23. Have you felt fear of social stigma due to disability of your child?

_____

_____

OBJECTIVE NO. 3 (EFFICACY OF THE FACILITY EXTENDED BY THE GOVERNMENT TO MITIGATE FAMILIES' SUFFERING FROM THE PROBLEMS)

24. Have you admitted your child in any special education centre?

_____

25. Have you felt relaxation after admitting your child in such institute?

_____

Has it minimized your burden of rearing and caring?

_____

26. Are you satisfied with the services rendered by this institute?

_____

27. What type of improvement did you find in your child after admitting in institute?

_____

28. What do you suggest for other parents who have such children for overcoming the problem?

_____

Thank you for participating in this research study

Closing time: _____

Check list for Interviews of Officials on

"*Effects of Child with Intellectual Disability on family in Khyber Pakhtunkhwa*"

Objective:

- To know about the efficacy of the facilities extended by the government to mitigate families' sufferings from the problems

Profile of Respondent:

25. Date of Interview:

26. Interview starting time: _____ _____ Interview ending time:

27. Name of Respondent (optional)

28. Address of Respondents:

29. _____

30. Contact Number (Optional) _____

1. What type of services is being provided in this Institute to children with Intellectual Disability?
2. What is your specific role or duty in this institute in dealing with children with ID?
3. Do you also provide counseling services to the parents of children with ID?
4. Are you satisfied with your role in dealing with the children with ID and their families?
5. Are you satisfied with the role of the Institute in delivering services to the children with ID?
6. What type of problems do you face during serving this job?
7. Do 18th amendments have brought any change in your job performance?
8. What are the limitations of these institutes in dealing with children having ID?
9. Is there any effective policy for social welfare in the province?
10. What is the role of parents in supporting children with ID in the institute?

Thank you for participating in this research study

Closing time: _____