

# UNIVERSITY OF PESHAWAR



Thesis on

## CAUSATIVE FACTORS OF MENTAL RETARDATION

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## Song Of Exceptional Children

Listen, the neglected once cries:  
Give us affection  
We are really from paradise  
When we serve the Nation, we feel  
Pleasures  
It is Heavenly Treasurer  
O, the Decision Makers of our fate  
Remember us also  
When you are building any gate  
Don't think us Barren land  
You know the flowers,  
Always Bloom in the Sand

*(Anonymous)*

## **Certificate**

I have the pleasure to certify that the thesis entitled "**Causative Factors of Mental Retardation**" is the personal work of Mrs. Monica Qamar Zaman. As far as I know, no other person was any way associated with its preparation. I also certify that I have gone through the draft thesis thoroughly and found it satisfactory for submission to the Department of Social Work, University of Peshawar in partial fulfillment of the requirements for the Degree of Ph.D. in Social Work.

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## **Declaration**

I do hereby declare that the thesis entitled "**Causative Factors of Mental Retardation**" submitted to the Department of Social Work, University of Peshawar, Pakistan for the Degree of Ph.D in Social Work is a completely new and original work done by me. It has not been submitted earlier partly or wholly to any University or Institution for any Degree or Diploma.

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*Researcher*

**MONIGAQAMAR ZAMAN**

## Justification

### Statement of the problem:

Like other social problems, mental retardation is one of the social problems of Pakistan. It is affecting not only the retarded child, it affect the family and the society as whole. In the past mentally retarded children were rejected by the society. Now a days still people didn't accept such children they hide them from the visitors because they feel shame. Some people think retarded child is a course from God. Such type of child born in their family because of family or their forefather's sins.

Researcher select this topic to find out the reasons of mental retardation why the children born with mental disabilities. Moreover researcher was interested to know the attitudes of retarded child's family, and neighbours. In Pakistan people prefer cousin marriages. Cousin marriages are practice mostly in NWFP and Balochistan. As there are so many reason for mental retardation, cousin marriages are also one reason, to find out the root cause of mental retardation. Researcher select the NWFP & Balochistan provinces because the local people of the said provinces practice cousin marriages. It is considered as prestige to get married within cousins.

People don't realize the consequences and the birth of a retarded child is considered as a blessing of the God. They don't even think that it might be due to some other reason.

The statistics also shows an alarming situation of disability in Pakistan. According to Disability Population Analysis National Census 1998, the total number of disabled people in Pakistan was 3293155. Out of this total, 8.06% were blind, 7.40% were hearing impaired, 19% were physically disabled, 14% were mentally retarded and insane, 8.21% were suffering form more than one disability and 43.33% were other kinds of disabilities which were not classified.

As far the institutions for special children are concerned, there are 127 institutions through out Pakistan. Out of this total strength, 53 are in Punjab, 48 are in Sindh, 22 are in NWFP and 4 are in Baluchistan.

Therefore keeping in view the severity of the problem the suffering, and its causes, it was considered important to conduct a study in order to find out the causative factors of mental retardation. This study will be helpful to find out the causative factors of mental retardation and on the basis of study findings, the researcher would be able to suggest remedial measures for the solution of the problem.

## Abstract Of The Study

The study "Causative factors of Mental Retardation" focuses on the children with mental disabilities. Any disability or abnormality is a great problem for the disabled and for his/her family. The area of study was limited to the Mental Retardation Center, Complex for Special Education, Balochistan, Complex for Special Education, Hayatabad, Peshawar & Sarhad School for Rehabilitation of Disabled, Peshawar.

### Objectives

- 1- To study the extent of congenital causes of mental retardation.
- 2- To study the environmental factors affecting the development of the mentally retarded.
- 3- Endogamy as a social factor to mental retardation.
- 4- Attitude of neighbors and other family members to the retarded child.

Mental retardation involves a general delay in the development of intellectual and adoptive abilities and affects most areas of social cognitive and language functioning. Mental retardation is generally assessed by a combination of testing on formal tests of intelligence and by observation of the child's adoptive functioning. The levels and I.Q scores of retardation are as Mild in between 55-70, Moderate 40-54, severe, 23-39, profound below 25 (Bniot Scale)

For this research, Sarhad Model School for Special Education and Complex for Special Education, Hayatabad Peshawar was selected from NWFP and Kiran Complex of Special Education School was selected from Baluchistan. All schools are under Federal Government. A total sample of 100 retarded children parents and their neighbors were selected for this research. Fifty Retarded children's parents & 50 next-door neighbors of mental retarded child were selected from both

provinces, to find out the main causative factors of mental retardation, and to know the societies mental approach i.e. their attitudes and their views about the retarded children. Mental retardation is a term, which covers all forms of less than normal intellectual functioning. (S. M. Bhatia, 1992)

The study was based on four assumptions,

**1<sup>st</sup> Assumption was:**

Families with poor Economic conditions have mal – nourished and poor health of the expecting mothers, which affects the fetus's mental and physical development.

**2<sup>nd</sup> Assumption was:**

Stress and strains on the expecting mothers affect the fetus and increases mental retardation in newborn children.

**3<sup>rd</sup> Assumption was:**

Cousin marriages weaken the genes of couple and they give birth to the mentally retarded children.

**Assumption No.4 was:**

Aged and physiological weak mothers give birth to mentally retarded children.

From different research techniques interview technique was used for data collection. For pre-testing 10 interviews were taken, unnecessary things like repetition of questions and language of the interview schedule was checked, after it, interview schedule was improved. After data collection it was classified and tabulated. The main inferences were:

- To know the causative factor of mental retardation
- To study the environmental factors affecting the development of the mentally retarded.
- Endogamy as a social factor to mental retardation.
- Attitude of retarded child's neighbor and his family members.

*CHAPTER - 1*

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*INTRODUCTION*

## Chapter – 1

### Introduction

Mental retardation is an important area for social research. It affects the social life of those suffering and of their family members as well.

This chapter deals with mental retardation, which is the focus of this study. Different scholars have defined it in different ways. It explores the sociological, psychological and religious perspectives of mental retardation. This chapter also includes the purpose, objectives, research questions, and assumptions of the study. Chapterization is made at the end of this chapter.

#### **Mental Retardation: An Introduction**

There has always been an individual in society whose behavior seems to be odd, unusual and bizarre to their fellows and who are called by them “mad” crazy and “Lunatic”, or a variety of similar terms.

Early definitions of retardation were generic in nature. Terms such as “fools” and “monsters” along with commentaries on persons who were lunatics or manifested other forms of mental illness, were used to describe a population encompassing the more observable forms of mental retardation and mental illness. Use of the term “fool” had its origin in the application of the Latin word *fatuus* which was used to define those who had no sense at all. The term monster is derived from the English word monster and Latin *Monstrous*, which originally mean a divine omen indicating misfortune (Burton, 1976)

The later Greek writings, the term *idios* (idiocy) meaning a private or peculiar person, came to be used to classify individuals who were mentally defective. The Romans used the term *imbecillis* (imbecile) to identify persons who were less severely retarded than the idiot.

The Mental Health Act of 1959 redefines the categories of mental handicap in the following way. The term severely subnormal, replaces the earlier definition of "idiot", the people which fall in this category are in a state of arrested or incomplete development which includes sub-normality of intelligence and is of such a nature or degree that the patient is incapable of living an independent life or of guarding himself against serious exploitations or will be so incapable. A second category of subnormal is defined as a state of arrested development of mind (such type of patient requires, medical treatment, care and special trainings) (Furieux, 1981).

Mental Retardation is the preferred term because it is simple term to describe a complex population (Donald, 1979). Mental Retardation does not define a single disease but a syndrome that can be produced by many causative factors, alone or in combinations. There is a considerable variety of conditions falling under the category of mental retardation. Impairment of intelligence is cardinal symptom of this syndrome impairment is usually observable in maturation, learning ability and social adjustment.

Mental retardation is a term which covers all form of less than normal intellectual functioning (Bhatia, S. M. 1992). The American Association on mental deficiency (1977) defines mental retardation as significantly sub-average intellectual functioning originating during the developmental period, accompanied by impairment in one or more of the following, maturation learning or social adjustment (Goldman, 1988).

### **Diagnostic Features**

#### **A. Definition**

1. The definition of mental retardation comes from work done by the American Association on Mental Retardation; it has basically been adopted by DSM IV.

a. "Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations ...[in several adaptive areas and]...manifests before age 18.

b. In more objective terms, mental retardation is defined by having a standardized IQ score at least two standard deviations below the mean and impairment in at least two out of ten areas of adaptive functioning when compared to peers of the same age and culture. The areas identified include: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. However, it should be kept in mind that these domains were not empirically selected and no single measure of adaptive function exists.

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: Communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18.

Significantly sub-average intellectual functioning means an IQ score of 70 to 75 or below on a standardized individual intelligence test. Related limitations refers to adaptive skill limitations that are related more to functional applications than other circumstances such as cultural diversity or sensory impairment.

#### B. Classification of mental retardation

1. Mental retardation is classified into four levels of severity based on intellectual impairment as measured by IQ scores. These

categories do not reflect functional capabilities; they have a standard error of measurement of approximately 5 points. The levels of severity, their IQ ranges, and their prevalence within the mentally retarded population are as follows:

- a. Mild (IQ 55-70) 85%
- b. Moderate (IQ 40-55) 10%
- c. Severe (25-40) 34%
- d. Profound (<25) 1-2%

The American Association on Mental Retardation (AAMR) offers the following definition:

**How does the new AAMR definition differ from earlier ones?**

The 1992 AAMR definition represents a significant change in the way those with mental retardation are viewed. Rather than describing mental retardation as a state of global incompetence, the new definition refers to a pattern of limitations, looking at how people function in various contexts of everyday life. This definition is based on four assumptions: (1) Valid assessment considers cultural and linguistic diversity, as well as differences in communication and behavioral factors; (2) The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for support; (3) Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; (4) With appropriate supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

Rather than limiting assessment to intellectual and adaptive skills, the current AAMR definition relies upon a multidimensional approach to describing individuals and evaluating their responses to present growth, environmental changes, educational activities, and therapeutic interventions:

Dimension	1:	Intellectual functioning and adaptive skills
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Dimension	II:	Psychological/emotional considerations
Dimension considerations	III:	Physical/health/etiological considerations
Dimension	IV:	Environmental considerations

In our Pakistani Society people mix-up the mentally ill and mentally deficient people. Mental deficiency is to be distinguished from mental illness in that sub-normality of intelligence present from birth or early childhood is an outstanding characteristic. The mentally ill suffers from other forms of mental handicap which arises for the most part during later adolescence or adult life due to social pressures.

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

- 1) Intellectual functioning level (I Q) is below 70 - 75.
- 2) Significant limitations exist in two or more adaptive skill area.
- 3) And the condition is present from childhood defined as age 18 or less (AAMR, 1992).

Hutt and Gibby (1972) say that Mental Retardation is a condition characterized by the faulty development of intelligence which impairs an individual's ability to learn and adopt to demands of society. Mental Retardation is a condition a syndrome, a symptom and a source of pain and bewilderment to many families. Its history dates back to the beginning of man's time on the earth. The idea of Mental Retardation can be found as far back in history as the therapeutic Papyri of Thebes (Luxor), Egypt, around 1500 B.C. Although some what vague due to difficulties in translation, these documents clearly refer to disabilities of the mind and body due to brain damage (Sheeren Berger, 1983). Mental Retardation is also a condition or syndrome defined by a collection of symptoms, traits and or characteristics. (It has been defined and renamed many times throughout history e.g. feeble-mindedness

and Mental deficiency were used as labels during the later part of the last century and in the early part of this century.

The plight of individuals with developmental disabilities has been dependent on the customs and beliefs of the era and the culture or locality. In ancient Greece and Rome, infanticide was a common practice. In Sparta, e.g. neonates were examined by a state council inspectors. If they suspected that the child was defective, the infant was thrown from the cliff to its death. By the 2<sup>nd</sup> century A.D individuals with disabilities, including children, who lived in the Roman Empire were frequently sold to be used for entertainment of the nobles. The dawning of Christianity led to a decline in these barbaric practices and a movement toward care for the less fortunate, all of the early religious leaders, Jesus, Buddha, Mohammad (Peace be Upon Him) and Confucius, advocated human treatment for the Mentally retarded, developmentally disabled or infirmed (Sheerenberger 1983).

During the middle ages (476-1799 A.D) the status and care of individuals with Mental Retardation varied greatly. Although more human practices evolved (i.e. decreases infanticide and the establishment of foundling homes), many children were sold into slavery, abandoned, or left out in the cold. Towards the end of this era, in 1690, John Locke published his famous work, entitled. "An Essay concerning human understanding". Locke believed that an individual was born without innate ideas. The mind is a tabularase, a blank state. This would profoundly influence the care and training provided to individuals with mental retardation. He also was the 1<sup>st</sup> to distinguish between Mental Retardation and mental illness (Doll. 1962). The most recent change in the definition of Mental Retardation was adopted in 1992 by the American Association of Mental Retardation; Mental Retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the

following applicable adoptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work, mental retardation manifests before age 18. (American Association on Mental Retardation 1992).

## **Historical background of Mental retardation**

### **The golden age in Ancient**

Nearly twenty – five centuries ago the first attempt in the history of Western civilization was made to view mental illness in a rational, systematic manner. The Greek Physician Hippocrates (460-357, B.C) established a medical practice separate from religion. His medicine was founded on his practical, clinical experience with sick people and not on any claim to supernatural powers. He included mental illness in his schemes of physical disease. In explaining mental illness, he compounded traditional views with his own observations and with good common sense. (Jack Roy, 1965).

### **The Dark Ages**

When Greece and Rome declined and fell, their learning and culture lay forgotten for over a thousand years. The early part of this period is known in history as the Dark ages. The specialists were religious leaders, and the common people were for the most part illiterate and superstitious. People believed that mental illness is a curse from God that allowed satan to put one of his demons in the body, and each type of mental and physical ailment had its special saint who was to intercede with God.

As the middle ages drew to a close, there was a gradual reawakening across Europe, beginning in Italy and ending in Germany. During this period men again became interested in nature and the world around them. They rediscovered the art and learning of ancient Greece and Rome.

## **The Reawaking**

A German Physician Theophrastus Bombastus Von Hohenheim, reintroduced medicine and the view that man is an integrated biological organism and that both physical and mental aberrations must be thought of in terms of a "Sick Person". This is a view that most successful clinical psychologists and psychiatrists hold today.

## **Age Of Reform**

In 1793 Philippe Pinel, a French Physician, was placed in charge of the Bicetre Asylum in Paris. His first decision as Director was to institute humane treatment, and his first action was to go into the wards and personally remove the chains. He changed a "madhouse" into one of the 1<sup>st</sup> mental hospitals. The general public opinion was that Pinel himself was a mad man who unchain dangerous beasts. Pinel's changes in the hospital were immediately for the best. Even the most incurable patients proved that they were not dangerous when treated with kindness, and remarkably enough some of those who had been in chains for years were soon on the road to recovery.

The age of reform may be said to have encompassed the whole nineteenth century. Almost every country had its dedicated pioneers and in every case they fought a desperate battle against those who they ignored the mentally sick people (Jack Roy, 1965, p.32-38).

During medieval times it was only in Arabia that the more scientific aspects of Greek Medicine Survived. The first mental hospital was established in Baghdad in A.D. 792, it was soon followed by others in Damascus and Aleppo. Mental disorders were apparently quite frequent throughout the middle ages and towards the end of the period, when medieval institutions began to collapse.

The spread of Christianity brought the hope to the handicapped. The institution of Jestinian provided care takers for imbeciles as well as for the sick and the idiotic.

While the decline of learning quite variables practices seem to have prevailed in Western Europe.

The two Verses are taken from the Holy Bible

“Ye have heard that it was said by them of old time, thou shalt not kill; and whosoever shall kill be in danger of the judgment.”

“But I say unto you, that whosoever is angry with his brother without a cause shall be in danger of the judgment; & whosoever shall say to his brother race, shall be in danger of the council, but whosoever shall say thou, fool, shall be in danger of help fir”. (Bible Mathew, 5<sup>th</sup> chapter verses, 21, 22) verses show's the punishment for those people which hate or dislike disables.

In 1247, Sheriff of London gave estate and Land to the Bishop and Church of Bethlem for the purpose of building a hospital. It was converted to mental asyllum in 1377, first patients transfer from an old store house located much too close to the king palace. Bethlem soon earned the title “Bedlum”, until 1770 Bethlem was one of the London's favorite tourist spot. First workhouse was established in 1771 in Philadelphia. In 1818 American Asylum for the deaf and dumb Hart Ford, began to provide the 1<sup>st</sup> recognized residential services intended specifically for people with Mental Retardation in the USA. After 1820, the smallest of the communities placed a greater reliance of the almshouse and then they gave them the name of Mental hospitals (Bruce, 1983). In 19<sup>th</sup> century the patients were treated as members of the families they ate all with the family and engaged in all family activities.

Many were given responsibilities such as baby sittings and other family chore. Many were employed in the town and on the farms. They could use all the community facilities, painting, drawing and gardening were encouraged. A change of science was viewed as beneficial, so the picnics and other outings were

organized. This approach was not adopted by other European countries until the late 19<sup>th</sup> century, and in the USA not until Charles Vaux during the 1930's. In 20<sup>th</sup> century England imbeciles were accorded legal status as wards of the king St. Vincent de Paul in France gathered the homeless, the bodily and mentally deficient into the Bicetre and other hospitals in Paris (H. H. Goldman, 1988).

The 1<sup>st</sup> institute to be established in the 19<sup>th</sup> century before 1913 the care of these people in the United Kingdom was in the hands of voluntary organizations, and a charge was made to the parents of their care, unless they were accommodated under the poor law act.

The mental deficiency act 1913 for the first time made local authorities responsible for the accommodation that might be needed. Patients were first admitted in 1933. The hospital was then designed Horthan Colony and a school, workshop, recreational facilities and delightful rural surroundings made it virtually a village community the act also made a distinction for the 1<sup>st</sup> time between mental deficiency and mental illness. Mentally handicapped children and adults were divided into four grades, idiot, imbecile, dull and backward and moral defective. The National Health Service Act, 1946 a possible step was taken, when all these colonies for the mentally handicapped were designated hospitals and came under the overall supervision of the regional health authorities.

In January 1962 a hospital plan for England and Wales was published (Ministry of Health 1962). This collected together the separate plans for hospital development produced by the fifteen regional hospital boards in a country for a period of fifteen years from 1960 – 1975 (H. H. Goldman, 1988).

By the end of this century levels of performance within the retarded population were beginning to be identified. The Binet, Simon Scale, first published in 1905, moved towards more precise definition of mental retardation by levels of performance (E. Philp. 1962).

Besides all these efforts, when state mental hospital and state institutions for the retarded were built in the late nineteenth and early 20<sup>th</sup> century, large numbers of retarded people were institutionalized. Such isolation and labeling furthered the stereotyped view of the mentally retarded as a homogenous group of subhuman, dangerous individuals who would commit crimes of all types, especially sex crimes, if allowed to roam free in the community, common fear among people was that the retarded would have an abnormally high reproductive rate and they can pollute the genetic pool of society. This reflected the mistaken belief that mental retardation is informally inherited. In California these fears were kept alive by the human betterment foundation of Pasadena (1943) California could claim responsibility for forty percent of all sterilization performed in the USA. Large number of state hospital patients were sterilized, including delinquents and retarded and epileptic patients.

As scientific data accumulated, public opinion began to shift. Studies showed that the mentally retarded have no general population and that their reproduction rate is actually somewhat lower than the general rate. Other common misconceptions still abound including the idea that mentally retarded people all are alike. The concepts of mental illness and the mental patient have an un-favorable public image all over the world. Attitudes have changed with use of proven techniques to help the retarded people, by increasing their potentials, improved care and training of retarded children, adolescents and adults, parental education has helped to change negative attitudes and the hopelessness surrounding the mentally retarded.

The new attitude that the retarded are deserving a normal environment reflects hope rather than despair, that the retarded are human beings with some rights and privileges as others. Many states have laws providing that individuals with IQ's below 70 who evidence socially incompetent or disapproved behavior can be classified as mentally retarded and committed to institutions. Mental retardation occurs among the children throughout the world, in its most severe forms, it is a

source of great hardship to parents as well as an economic and social burden on the community (Coleman, 1988).

### **Rational of the study**

The researcher is a professional social worker and is with a university as a lecturer. During studies and field work observation, the researcher had to deal with different types of disabled particularly the mentally retarded people. Dealing with such sub-humans, lunatics insane, mad, crazy people, the terms used by lay people for these abnormal persons, realized the researcher to go through their life. Researcher decided try to find out the "why" of this problem

All over the world this fact is realized that cousin marriages are the main cause of different disabilities. According to world health organization the world's 20% people are living in small groups where they are bound in kinship ties, they prefer cousin marriages. This marriage practice as consanguineous marriage. In Arabian countries 20-50% people practice family marriages.

According to National census 1998, the total number of disabled persons in Pakistan was 3293155, out of this total, 8.06% were blind, 7.40% were hearing impaired, 19% were physically disabled, 145 were mentally retarded and insane, 8.21% were suffering from more than one disability and 43.33% were other kinds of disabilities which were not classified.

The main causes of cousin marriages in Arabia and Islamic countries are:

- 1- A newly wedded girl can easily adjust in a new setup of in-laws; who are already known to her being her relative.
- 2- Dowry which is considered as a problem due to the demand from the groom's side, can also be worked out.
- 3- It is considered that marriage within the families or the cousin marriage make the families grow in strong families.

- 4- Land owner did not allow their children to marry outside the family, they don't allow outsiders to take ownership of their land.
- 5- Cousins know each other's families very well from their childhood. Their understand develop more easily and they take care of each other.
- 6- The parents of bride give reason for cousin marriage i.e. their daughter will not go far away from them. Relatives will give her more attention and love.

The Genetic Councilor says cousin marriages weaken the genes, which cause genetic disorders and other disabilities, weaken genes give birth to weak children specialist says every family face's medical problems. If interfamily marriages practices the relative problems became Absolute problems. The children inherit the diseases through genes.

#### **Marriage in Islam:**

Few well of families give different reasons for cousin marriages in the name of Islam.

Imam of Faisal Mosque, Vice-Chancellor of Women Institute for Science and humanity and Daawa Academies, Director says that:

“In Islam there is no compulsion for cousin marriages.”

In developed countries like America cousin marriages are strictly prohibited. Few states allow the cousins for marriage with different restrictions e.g. they will not give birth to children. The genetic counseling is must for the couples. (Daily News Paper Pakistan 10<sup>th</sup> May 2005).

The main purpose of this study is to find out the Causative Factors of Mental Retardation. In Pakistan there are many beliefs about the mentally retarded people.

The study is focus on the two provinces Balochistan & N.W.F.P to collect the information according to the objectives of the study. In Pakistan most areas like Balochistan & N.W.F.P are practicing endogamy. It has many reasons, e.g. like dowry, land, tribal factors, sect, and creed. Carter (1969) many studies shown the chromosomal disorders, low intelligence & blood diseases due to endogamy

inheritance. Study is focused on these issues and tested these causes by interviewing them.

In Pakistan people are not much aware of the problem of mental retardation. Through this research, awareness can be created among the people. The parents who have retarded child the causes of retardation can be discussed with them and if they want to plan for other child genetic counseling and guidance can be provided to them.

### **Objectives of the study**

#### **1- To study the extent of congenital causes of mental retardation.**

Mental retardation is a social problem, which is caused by congenital diseases. Congenital diseases are due to many causes, the most common cause is weak genes of parent's age of mother (40+), poor health and poor economic condition of mother can be the cause of mental retardation. If mothers took medicines during pregnancy it also affects the brain of the child. There are approximately 6,000 known genetic disorders whose effects are also related to mental retardation.

Almost all birth defects involve impaired central nervous system functioning.

Doctors have found many causes of mental retardation. The most common are genetic conditions. Sometimes mental retardation is caused by abnormal genes inherited from parents, errors at the combination of genes, or other reasons mental retardation can result when child can not develop before birth, e.g. there may be a problem with the baby's cells divided as it grows. A woman who drinks alcohol, or get an infection like rubella during pregnancy may also have a baby with mental retardation.

#### **2- To study the environmental factors affecting the development of the mentally retarded:**

Mental Retardation is not a single homogeneous disease, there are many known causes, both inherited and environmental. Problems during labor and birth, such as not getting enough oxygen, child may have mental retardation. Diseases like whooping cough, measles, meningitis can cause mental retardation. It can also be caused by extreme malnutrition, not getting enough medical care, or by being exposed to poisons like lead or mercury.

### **3- Endogamy or cousin marriages as a social factor to mental retardation.**

All over the world this fact is realized that cousin marriages are the main cause of different disabilities. According to World Health Organization World's 20%. People prefer cousin marriages. Medical science give name this marriage as consanguineous marriage. 20 – 50% people in Arabian countries practice cousin marriages. The Genetic Councilers says cousin marriages weaken the genes<sup>1</sup>. Weak genes give birth to the weaken children. In many developed countries like America cousin marriages are strickly prohibited. Few states give permission for cousin marriage with the condition i.e. the wedded couple did not give birth to children.

In Pakistan and Islamic countries prefer cousin marriages. According to National census 19998 the Mental Retarded and Insane were 14% of the total population. Now a days the number is decreased because of the awareness about this genetic disease.

### **4- Attitude of neighbors and other family members to the retarded child.**

Birth of disabled child become a great sorrow and problem for the family. They become depressed, many families think's the birth of Retarded child is

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<sup>1</sup> Syed Naqvi Kazami, Article on Cousin Marriages. Magzine Report: Daily News Paper, Pakistan. 10<sup>th</sup> May 2005.

the punishment from God. In the past families put such children in chains. In these days parents didn't show such type of attitude but they feel shame having mentally retarded child. When visitors come to their house they put their retarded child behind the walls. Parents ignore their retarded child. Most of the parents didn't allow the child to participate in social activities

The neighbours attitude is not good with retarded children. Most of the people make fun of such children. They did not want to make family relations with mentally retarded child's family, because of stigma the society given them.

### **Assumptions**

- 1. Families with poor economic conditions have mal-nourished and poor health of the expecting mothers which affects the fetus's mental and physical development hence giving birth to mentally retarded children.**

Healthy mother's give birth to the healthy children. If mother's health is not good she is not taking balance diet, it will effect at the fetus. The fetus's growth will become slow. If mother is mal-nourished she belongs to economically poor family and did not afford balance diet she will give birth to mentally and physically weak children.

- 2. Stress & strains on the expecting mothers affect the fetus & increase mental retardation in newborn children.**

Mother's home environment her stresses and strain during pregnancy effect's at the brain of child. During pregnancy if all the time she is in depressed states, chemical changes occur in her blood, her blood pressure increases or some times decreases, these all changes effect at fetus's growth and activity. His brain's tiny nerves which are in the stage of development damaged or sometime their growth stopped due to different reasons and the child become mentally retarded.

- 3. Repeated cousin marriages weaken the genes of couples and they give birth to the mentally retarded children.**

Cousin marriages practice not only in Pakistan it practices in developed countries also. The genetic councilors says repeated cousin marriages weaken the genes of the couples. Weak genes effects at the child, in result child born with different disabilities the most common is mental retardation.

#### **4. Aged & physiological weak mothers give birth to mentally retarded children.**

Age of the mother effects at child health. Aged mothers or 40 + mother's genes and health become weak they give birth to weak mentally and physically children.

### **Research questions to be investigated**

In this study, an effort would be made to answer the following questions:

- 1) How mal-nourishment of the expecting mothers leads to the birth of mentally retarded children?
- 2) How stress and strain of the expecting mothers increases the possibility of giving birth to mentally retarded child?
- 3) Can interfamily marriages a cause of mental retardation?

### **Universe of the study**

The area of study was limited to three special education schools. Two of them were taken from Peshawar and one was from Quetta. The schools were

1. Sarhad Model School for Special Education, University Town, Peshawar
2. Special Education Complex, Hayatabad, Peshawar
3. Kiran Complex for Special Education Quetta

### **Organization of the thesis**

This report consists of five chapters. Chapter one is Introduction. It highlights the meaning of mental retardation, which is the focus of the study. This chapter also

includes purpose of the study, objectives, assumptions, and research questions and limitation of the study.

Chapter two deals with literature review about mental retardation. It starts from historical background of mental retardation. It further includes the factors influencing mental activity and its impact on individual's life. It also highlights the rehabilitation of the mentally retarded children.

Chapter three is methodology of the study. It covers universe of the study, sample size, sample technique, tools of data collection, time schedule, and pre-testing of the questionnaire.

Data has been analyzed in chapter four. This chapter is further divided into two main parts. Part – A covers information from mothers and Part – B deals with information from neighbours.

Chapter five is also divided into two main parts, i.e. conclusions and suggestions/recommendations. Conclusion of the study is made in Part – One whereas suggestions/recommendations are made in Part-two.

Annexure is given at the end of the research report, which include glossary, bibliography, and samples of interview schedules.

*CHAPTER - 2*

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*REVIEW LITERATURE*

## **Chapter – 2**

### **Review of Literature**

This chapter deals with the review of literature related to mental retardation. It covers the historical background of mental retardation in different ages. Furthermore, it explains the factors, which influence the mental activity and its impact on individual life.

#### **Factors Influencing Mental Activity And Its Impact On Individuals Life**

##### **Etiologic Factor**

Robinson and Robinson (1965) stated (in the book “The mentally retarded child”), that retardation seems to be primarily a function of the hereditary endowment, and it seems to be the result of a complex interaction between genetic endowment and multitude of environmental factors.

A particular etiologic process may affect the child at any stage of the life span. It may occur at the time of conception, at any point in uterus during birth, or at any time after birth the child may suffer from some thing, which happens in a single instant, while another handicap may be caused by a complicated series of interrelated events occurring over several months or years. In another the defect may be diffused throughout the central nervous system.

A Mongoloid child suffers the effects of extra chromosomes material, which so far known, inevitable produces some degree of defect in the developing organism.

William (1956) said that heredity and environment are the basic causes of mental retardation. Most psychologists emphasized at the importance of heredity factor, but they did not deny the role of brain damage on the social emotional variables as these influence not only the intelligence but the overall adjustment pattern of child.

## **Sex Chromosomes Abnormalities**

These abnormalities, which range from the absence of a sex chromosome ( $X_0$ ) to the presence of multiple sex chromosomes ( $xxxxy$ ) are often accompanied by mental retardation. In Turner's (the founder) Syndrome ( $45, X_0$ , Karyotype) findings include sterility and, occasionally, retardation. Klinefelter's syndrome ( $xxy$ ) occurs in one in 11 hundred male births and characterized by sterility gynecomastio, and neuro developmental abnormalities. (Barr. 1964)

## **Genetic Disorders**

Genetics is "the science that studies the principles and mechanics of heredity, or the means by which traits are passed from parents to offspring" (Glanze, 1996). Through genetics a number of specific disorders have been identified as being genetically caused. One example is fragile X syndrome, a common genetic cause of mental retardation, which is caused by the presence of a single non-working gene (called the FMR-1 gene) on a child's X chromosome.

Genetics originated in the mid-19th century when Gregor Mendel discovered over a ten year period of experimenting with pea plants that certain traits are inherited. His discoveries provided the foundation for the science of genetics. Mendel's findings continue to spur the work and hopes of scientists to uncover the mystery behind how our genes work and what they can reveal to us about the possibility of having certain diseases and conditions. The scientific field of genetics can help families affected by genetic disorders to have a better understanding about heredity, what causes various genetic disorders to occur, and what possible prevention strategies can be used to decrease the incidence of genetic disorders.

## **Can a person's genes cause mental retardation?**

Some genetic disorders are associated with mental retardation, chronic health problems and developmental delay. Because of the complexity of the human body, there are no easy answers to the question of what causes mental retardation. Mental retardation is attributable to any condition that impairs development of the

brain before birth, during birth or in the childhood years (The Arc, 1993). As many as 50 percent of people with mental retardation have been found to possess more than one causal factor (AAMR, 1992). Some research has determined that in 75 percent of children with mild mental retardation the cause is unknown (Kozma & Stock, 1993).

The field of genetics has important implications for people with mental retardation. Over 350 inborn errors of metabolism have been identified, most of which lead to mental retardation (Scriver, 1995). Yet, the possibility of being born with mental retardation or developing the condition later in life can be caused by multiple factors unrelated to our genetic make-up. It is caused not only by the genotype (or genetic make-up) of the individual, but also by the possible influences of environmental factors. Those factors can range from drug use or nutritional deficiencies to poverty and cultural deprivation.

#### **How often is mental retardation inherited?**

Since the brain is such a complex organ, there are a number of genes involved in its development. Consequently, there are a number of genetic causes of mental retardation. Most identifiable causes of severe mental retardation (defined as an IQ of 50 or less) originate from genetic disorders. Up to 60 percent of severe mental retardation can be attributed to genetic causes making it the most common cause in cases of severe mental retardation (Moser, 1995). People with mild mental retardation (defined as an IQ between 50 and 70-75) are not as likely to inherit mental retardation due to their genetic make-up as are people with severe mental retardation. People with mild mental retardation are more likely to have the condition due to environmental factors, such as nutritional state, personal health habits, socioeconomic level, access to health care and exposure to pollutants and chemicals, rather than acquiring the condition genetically (Nelson-Anderson & Waters, 1995). Two of the most common genetically transmitted forms of mental

retardation include Down syndrome (a chromosomal disorder) and fragile X syndrome (a single-gene disorder).

### **What causes genetic disorders?**

Over 7,000 genetic disorders have been identified and catalogued, with up to five new disorders being discovered every year (McKusick, 1994). Genetic disorders are typically broken down into three types:

- 1) Chromosomal,
- 2) Single-gene and
- 3) Multifactorial.

Chromosomal disorders affect approximately 7 out of every 1,000 infants. The disorder results when a person has too many or too few chromosomes, or when there is a change in the structure of a chromosome. Half of all first-trimester miscarriages or spontaneous abortions occur as a result of a chromosome abnormality. If the child is born, he or she usually has multiple birth defects and mental retardation.

Most chromosomal disorders happen sporadically. They are not necessarily inherited (even though they are considered to be genetic disorders). In order for a genetic condition to be inherited, the disease-causing gene must be present within one of the parent's genetic code. In most chromosomal disorders, each of the parent's genes are normal. However, during cell division an error in separation, recombination or distribution of chromosomes occurs. Examples of chromosomal disorders include Down syndrome, Trisomy 13, Trisomy 18 and Cri du chat.

Single-gene disorders (sometimes called inborn errors of metabolism or Mendelian disorders) are caused by non-working genes. Disorders of metabolism occur when cells are unable to produce proteins or enzymes needed to change certain chemicals into others, or to carry substances from one place to another. The cell's inability to carry out these vital internal functions often results in mental retardation. Approximately 1 in 5,000 children are born with defective enzymes

resulting in inborn errors of metabolism (Batshaw, 1992). Although many conditions are generally referred to as "genetic disorders," single-gene disorders are the most easy to identify as true genetic disorders since they are caused by a mutation (or a change) within a single gene or gene pair.

### **Down's Syndrome**

Normal person's receives 46 chromosomes from their parents, 23 chromosomes from mother and 23 chromosomes from father. Down's syndrome person got one extra chromosome (47 chromosomes)

Combinations of multiple gene and environmental factors leading to mental retardation are called multifactorial disorders. They are inherited but do not share the same inheritance patterns typically found in single-gene disorders. It is unclear exactly why they occur. Their inheritance patterns are usually much more complex than those of single gene disorders because their existence depends on the simultaneous presence of heredity and environmental factors. For example, weight and intelligence are traits inherited in this way (Batshaw, 1992). Multifactorial disorders are very common and cause a majority of birth defects. Examples of multifactorial disorders include heart disease, diabetes, spina bifida, anencephaly, cleft lip and cleft palate, clubfoot and congenital heart defects.

### **How are genetic disorders inherited?**

Genetic disorders can be inherited in much the same way a person can inherit other characteristics such as eye and hair color, height and intelligence. Children inherit genetic or hereditary information by obtaining genes from each parent. There are three common types or modes of inheritance: dominant, recessive and X-linked (or sex-linked).

Dominant inheritance occurs when one parent has a dominant, disease-causing gene which causes abnormalities even if coupled with a healthy gene from the

other parent. Dominant inheritance means that each child has a 50 percent chance of inheriting the disease-causing gene.

### **Metabolic Abnormalities**

These are primarily by endocrine disorders or by recessive gene abnormalities. The inborn errors of metabolism represent fewer than 10% of all known hereditary defects. This is due to iodine deficiency in mothers in infants.

Dr. Joseph Hollowell said the people who get less iodine in their diet, they put themselves at increased risk of mental retardation. Iodine is a crucial nutrient for production of thyroid hormone, which plays an important role in brain development. Goiter is common in those people, who have iodine deficiency. (Streissguth, 1991)

### **Proder – Willi Syndrome**

It is a complex genetic disorder that includes short stature, mental retardation, learning disabilities, in-complete sexual development, characteristic behavior problems, low muscle tone and an involuntary urge to eat constantly, which coupled with a reduced need for calories leads to obesity. Children need special education and services such as speech and occupational therapy. (Holm, V. 1993).

### **Disorders Of Amino Acid Metabolism**

The best known example of the inborn metabolic errors is phenylketonuria. It has an incidence of one in 15,000. The disorder is due to deficiency or defect in the liver enzyme phenylalanine hydroxylase, which gives rise to series of biochemical abnormalities starting with accumulation of ingested phenylalanine (an essential amino acid) in the body. The people with this disorder get disturbed behavior.

### **Disorder Of Carbohydrate Metabolism**

There are two major types:

Galactosemia results from an inborn absence or deficiency of the enzyme galactose - 1 - phosphate uridylyltransferase. This enzyme is necessary for the metabolism of galactose (found in milk) and its absence results in progressive mental deterioration, cataracts and hepatic insufficiency.

- a) Type I is caused by a deficiency of the enzyme glucose phosphates which results in accumulation of glycogen in the liver.
- b) Type II which cause death in infancy.

## **Prenatal factors**

### **Infectious diseases**

Such as rubella (preventable with immunization), Toxoplasmosis and cytomegalo virus inclusion disease (the most frequent cause of retardation).

### **Radiation**

Ionizing Radiation effects on sex cells, body cells and tissues. Radiation may act directly on the fertilized ovum or may produce gene mutations in the sex cells of either or both parents which in turn may lead to defective offspring.

By Turner (1988) X-rays are also harmful for the expected mother because the X-rays effects at baby's parts of the body.

### **Alcohol (Social causes)**

If a pregnant mother takes alcohol during pregnancy, it is not only carried to all organs and tissues, but also to placenta, where it easily crosses through the membrane separating maternal and fetal blood systems.

The liver of a fetus cannot process alcohol at the same as that of the adult. The adults rate is of one ounce every two hours.

Alcohol can impair growth of the infant and many life-long problems occur in the child. .e.g.

1. Low birth weight
2. Small head size
3. Narrow eye slits
4. Flat mid face
5. Loss of groove between nose upper lip
6. Central nervous system problems.
7. Mental Retardation.
8. Poor sucking response
9. Sleep disturbance
10. Developmental delays
11. Short attention span.
12. Learning disabilities
13. Bones and joint problems
14. Genital defects
15. Heart defects.

### **Socio-Cultural Factors**

Socio-cultural factors, nutrition of the mother and the medical care she receives during pregnancy can influence the development of the fetus in many indirect ways. All these factors are related to the incidences of complications during pregnancy and premature birth of a baby. It can cause brain damage of the baby before and during birth.

### **Iron Deficiency**

Iron deficiency is one of the most common known nutritional deficiencies worldwide. In pregnant women, iron deficiency anemia during the first two trimesters of pregnancy is associated with a two fold increased risk for a pre-term delivery, and three fold increased for delivering a low – birth weight baby. Both of these conditions are closely associated with mental retardation of newborn.

Iron deficiency causes developmental delays and behavioral disturbances.

## **Iodine**

Iodine is a crucial nutrient for production of thyroid hormone, which plays an important role in brain development. If pregnant mother is deficient in iodine her fetus may be impacted, and she puts her child at increased risk of mental retardation and Goiter.

## **Background Of The Mother**

The possibility exists that factors operating long before the pregnancy, even in the early childhood of the prospective mother may affect her reproductive efficiency. One of the most important areas is childhood nutrition. (Mashland, 1958)

If mother has poor eating habits or malnutrition, her child will be weak and anemic by birth.

## **Environmental Factors (Postnatal Causes)**

This very large category includes traumatic, metabolic, infections, toxic and other cause of brain damage, hemorrhages, hypothyroidism, encephalitis, exposure to carbon monoxide, post immunization encephalopeterus from blood incompatibilities or other hemolytic disease. (Goldman. 1988).

## **Infections**

Infections after birth also the common cause of mental retardation.

## **Environmental Deprivation**

Other kind of environmental factor is improper handling and lack of loving care during the first year of life. Institutionalized infant appear to develop permanent psychomotor and intellectual deficiency (Blackwell, 1979).

## **Social & Cultural Factors**

There are behavioral differences between those in one geographic region and those in another. Kardiner pointed out tensions from hunger, the need for support, for

emotional responses. If the sibling's relatives or other persons take care of the child, the ego of the child is feeble in development and filled with anxiety (Sarason, 1959).

There is considerable evidence that a poor cultural environment retards intellectual growth. The syndrome familial cultural retardation is probably the result of the interaction of several of these factors.

### **Somatogenic Factors**

Somatogenic factors in some way disrupt the functioning of the central nervous system.

#### **Anoxia**

Shortage of oxygen in the blood supply to the brain is the commonest cause of brain damage.

It may be difficult to get the infant to breathe after birth, and undue delay will certainly result in irreversible damage to the brain.

#### **Hypoglycemia (Low blood sugar)**

A continued very low level of blood sugar of mother may give rise to convulsion and may result in permanent brain damage.

#### **Amniocentesis**

A small sample (10 ml) of amniotic fluid drawn through the mother's abdomen contains evidence of both the maturity and the health of the fetus. It usually affects at the lungs (immature lung development is the crucial factor in hyaline membrane disease) of the fetus.

## **Asphyxia**

The direct cause of perinatal asphyxia is usually asphyxia. Pressure on the fetus brain from uterine contractions is believed to slow the fetal heart rate by means of a vagal nerve effect.

## **Birth injury**

A prolonged or precipitous labor involving a premature infant during a vaginal delivery may lead to traumatic cerebral hemorrhage.

## **Effects Of Mental Retardation On Individual's Life**

**What are some typical characteristics of children with mental retardation?**

Among individuals with mental retardation, there is a wide range of abilities, disabilities, strengths, and needs for support. It is common to find language delay and motor development significantly below norms of peers who do not have mental retardation. More seriously affected children will experience delays in such areas of motor-skill development as mobility, body image, and control of body actions. Compared to their non-disabled peers, children with mental retardation may generally be below norms in height and weight, may experience more speech problems, and may have a higher incidence of vision and hearing impairment.

In contrast to their classmates, students with mental retardation often have problems with attention, perception, memory, problem-solving, and logical thought. They are slower in learning how to learn and find it harder to apply what they have learned to new situations or problems. Some professionals explain these patterns by asserting that children with mental retardation have qualitatively different deficits in cognition or memory. Others believe that persons with mental retardation move through the same stages of development as those without retardation, although at a slower rate, reaching lower levels of functioning overall.

Many persons with retardation are affected only minimally, and will function only somewhat slower than average in learning new skills and information.

### **What are some educational implications?**

For younger children with mental retardation and persons with more extensive limitations in their adaptive skills, teachers may find that hands-on materials are more meaningful than pictures and demonstrations more instructive than verbal directions. Teachers should build on students' existing skills by teaching easier tasks before more complex tasks; breaking longer, new tasks into small steps; and prompting or shaping accurate performance. Teachers should help students develop rules and provide opportunities for them to apply or transfer what they have learned. They can help students generalize by using multiple examples and settings.

It will help students with mental retardation if shorter and distributed (not massed) learning sessions are provided in the instructional process, especially school, living, community, and work environments. From an early age, life skills including daily living, personal/social skills, and occupational awareness and exploration should be taught. Instruction in leisure and recreational opportunities and skills also should be a part of the educational program along with vocational preparation and training for adult living. As much as possible, children and youth with mental retardation should be educated inclusively: in schools, classrooms, and activities with their non-disabled peers.

### **Behavior problems**

Severely retarded children need to be taught each aspect of social behavior. Children also learn early to read expression of approval or disapproval in their parent's tone and posture.

A behavioral management program depends upon psychologist's systematic approach to be successful

## **Sleep Disturbance**

Some retarded children get sleeping problems. Children with severe emotional problems are typically disturbed by phobias and terrors at night. The programs are individualized but generally involve arranging the home environment to permit the child's nighttime tantrums or activity to be self-limited, with little parental involvement. Drugs play an important role in treating refractory sleep problems.

## **Body Control Problems**

Children, who cannot support and control their head, a well supporting position is vital. Special seating may be a matter of providing an ordinary chair of the right height so that the child's feet touch the ground.

# **Habilitation & Rehabilitation Of The Mentally Retarded Children**

## **Introduction**

This part differentiates habilitation and rehabilitation, it explains the services, which are given to the mentally retarded persons. Chapter also covers the history and present situation of special education in Pakistan.

W.H.O has defined health as the best hope for the mentally retarded which lies in special education training and rehabilitation. There is likewise a great need for special institutions, training schools and rehabilitation centers for the mentally retarded. With patience, perseverance, persistence, personal care and abundance of love, they can be trained and taught to look after themselves, move about, even travel by themselves, be economically self supporting or otherwise helpful to the family. Every human has some capacity for learning.

Special education means specially designed instructions, which meet the unique needs of an exceptional child. Special material, teaching techniques and equipments are required in special education.

Special education may be provided according to several types of administrative plans.

There have always been exceptional children, but there have not always been special educational services to answer their needs during the closing years of the eighteenth century. Early in the nineteenth century, the first systematic attempts were made to educate “idiotic” and “insane” children those who today are called mentally retarded and emotionally disturbed.

The historical roots of special education are in the early 1800's. Contemporary educational methods for exceptional children can be traced directly to technique: pioneered during that era.

Jean Mare Gaspard I. Tad (1775-1838) a French Physician who was an authority on diseases of the ear and on education of the deaf, is the person to whom most historians trace the beginning of special as we know it today.

Montessori, the first woman in Italy to receive a Medical degree, became now not only as educator of the mentally retarded but as an advocate of early education for normal children. (Montessori, 1912-1917).

### **The Concept of Habilitation**

In Scandinavian medicine the term 'habilitating' or habilitation is often used synonymously with or in addition to rehabilitation. Habilitation not only implies the need to restore functional independence by a systematic intervention process but it also provides support in developing new functional abilities and coping skills. Just like all people, individuals with functional impairments are perceived as going through a life-long developmental process with varying needs and priorities.

While rehabilitation has traditionally focused on lost physical functionality based on normative standards, habilitation indicates a prospective, future-oriented approach. Limitations in physical functions are not ignored but are considered

within the context of the individual's current life and future goals. Instead of focusing on "deficits" habilitation seeks to uncover individuals' resources, abilities and strengths. Habilitation is the goal-oriented assistance to build and maintain functions, social integration and quality of life of people with disabilities (Ozer & Kroll, 2003). The concept of 'habilitation' may be more appropriate being a prospective, integrative framework to address the complex nature of disability in health care delivery, education, research, and policy.<sup>2</sup>

Habilitation is usually defined as a process by which various professional services are utilized to help a disabled individual make maximum use of his capacities in order that he might learn to function more effectively recent phenomenon, first appears in mind during nineteenth century. It was seriously challenged at close of that century, tentatively resurrected a few decades later, then given unqualified endorsement by some during the 1970's. although periods of concern for the mentally retarded occurred through out the ages, there is little indication, as Kanner (1969) pointed out that they were regarded by physicians as part; of their medical responsibility, the same said of educators. In the wake of eighteenth and nineteenth century humanitarianism, the alienist pineal cast the chains from the insane in Paris, and the reformer Dorothea. L. Dix made her impassioned Plea to the Massachusetts Legislature on behalf of the mentally defective and mentally deranged. In the aftermath of such concern over the poor, the insane, and the criminal, the idea of teaching the mentally retarded was germinated. The early teachers of the retarded were as convinced of the basis degeneracy of their charges as they were of their potential for improvement with appropriate training. The early maintained a totally. Christian view of their labors. They were saving idiots who, according to Sequin, knows nothing, can do nothing, cannot even desire to do anything, and according to How represented the lowest classes of human

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<sup>2</sup> [http://www.healthwellness.org/training/sciconf/sciconf\\_presentations/kroll/slide10.htm](http://www.healthwellness.org/training/sciconf/sciconf_presentations/kroll/slide10.htm).

organisms, "breathing masses of flesh, fashioned in the shape of men, but shorn of all other human attributes".

This, then the spirit of habilitation in the mid nineteenth century both in the Europe and in the United States. The attitude was positive, and optimism prevailed. Mentally retarded persons could be trained sufficiently to permit them to function in normal community. If the concept of cure was not a part of the new spirit, it did not show the effort. Harvey B. Wilbur, who started the first American private school at Bare, Massachusetts, and later become superintendent of the experimental school at Albany, New York, slated a most reasonable goal for the rehabilitation programs. As institutions grew in size, the tone of the reports and papers emanating from them changed radically from the laudatory. Case histories of success with the physiological of operation and reluctant acknowledgement that many mentally retarded would require life long care. In 1983, Walter E. Fernald, superintendent of the Massachusetts school for the feeble-minded, described the typical American institution as divided into section, the school or educational department.

### **Rehabilitation of Mentally Retarded**

Mentally retarded persons are individual and as such have individual needs. Services must be able to adopt to meet individual needs, which in turn presuppose a certain flexibility of organization of special importance in this context is consideration of the emotional needs of the retarded, which should be fundamental to all rehabilitation programs.

### **Assessment**

Assessment of a child suspected of having a developmental disability, such as mental retardation, may establish whether a diagnosis of mental retardation or some other developmental disability is warranted, assessing eligibility for special educational services, and/or aid in determining the educational or psychological

services needed by the child and family. At a minimum, the assessment process should include an evaluation of the child's cognitive and adaptive or everyday functioning including behavioral concerns, where appropriate, and an evaluation of the family, home, and/or classroom to establish goals, resources, and priorities.

Globally defined, child assessment is the systematic use of direct as well as indirect procedures to document the characteristics and resources of an individual child (Simeonsson & Bailey, 1992). The process may be comprised of various procedures and instruments resulting in the confirmation of a diagnosis, documentation of developmental status, and the prescription of intervention/treatment (Simeonsson & Bailey, 1992). A variety of assessment instruments have been criticized for insensitivity to cultural differences resulting in misdiagnosis or mislabeling. However, assessments have many valid uses. They allow for the measurement of change and the evaluation of program effectiveness and provide a standard for evaluating how well all children have learned the basic cognitive and academic skills necessary for survival in our culture. Given that the use of existing standardized instruments to obtain developmental information as part of the assessment process may bring about certain challenges, there does not appear to be a reasonable alternative (Sattler, 1992). Thus, it becomes necessary to understand assessment and its purpose so that the tools which are available can be used correctly, and the results can be interpreted in a valid way.

The four components of assessment (Sattler, 1992), norm-referenced tests, interviews, observations, and informal assessment, complement each other and form a firm foundation for making decisions about children. The use of more than one assessment procedure provides a wealth of information about the child permitting the evaluation of the biological, cognitive, social and interpersonal variables that affect the child's current behavior. In the diagnostic assessment of children, it is also important to obtain information from parents and other significant individuals in the child's environment. For school-age children,

teachers are an important additional source of information. Certainly, major discrepancies among the findings obtained from the various assessment procedures must be resolved before any diagnostic decisions or recommendations are made. For example, if the intelligence test results indicate that the child is currently functioning in the mentally retarded range, while the interview findings and adaptive behavior results suggest functioning in an average range, it would become necessary to reconcile these disparate findings before making a diagnosis.

### **Cognitive/Developmental Assessment Tools**

*Bayley Scales of Infant Development - Second Edition (Bayley, 1993)*: The Bayley Scales is an individually administered instrument for assessing the development of infants and very young children. It is appropriate for children from 2 months to 3½ years. It is comprised of three scales, the Mental Scale, the Motor Scale, and the Behavior Rating Scale. The Mental Scale assesses the following areas: recognition memory, object permanence, shape discrimination, sustained attention, purposeful manipulation of objects, imitation (vocal/verbal and gestural), verbal comprehension, vocalization, early language skills, short-term memory, problem-solving, numbers, counting, and expressive vocabulary. The Motor Scale addresses the areas of gross and fine motor abilities in a relatively traditional manner. The Behavior Rating Scale is used to rate the child's behavioral and emotional status during the assessment. Performance on the Mental and Motor Scales is interpreted through the use of standard scores (mean = 100; standard deviation = 15). The Behavior Rating Scale is interpreted by the use of percentile ranks. The Bayley Scales were standardized using a stratified sample of 1,700 infants and toddlers across 17 age groupings closely approximating the U.S. Census Data from 1988. The manual includes validity studies and case examples. The Bayley Scales is one of the most popular infant assessment tools. It can also be used to obtain the developmental status of children older than 3½ who have very significant delays in development and cannot be evaluated using more age-

appropriate cognitive measures (e.g., a 6 year old with a developmental level of 2 years).

*The Differential Ability Scales (DAS) (Elliott, 1990)*: The DAS consists of a battery of individually administered cognitive and achievement tests subdivided into three age brackets: lower preschool (2 ½ years to 3 years, 5 months), upper preschool (3 ½ years to 5 years, 11 months), and school age (6 years to 17 years, 11 months). The cognitive battery focuses on reasoning and conceptual abilities and provides a composite standard score, the *General Conceptual Ability (GCA)* score. Verbal and Nonverbal cluster standard scores and individual subtest standard scores are also available. The DAS has several advantages over other similar measures. It has a built-in mechanism for assessing significantly delayed children who are over the age of 3 ½ years. It can also provide information comparable to other similar instruments in about half the time. Finally, it is very well standardized and correlates highly with other cognitive measures (i.e., the Wechsler Scales).

*Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R) (Wechsler, 1989)*: The WPPSI-R can be utilized for children ranging in age from 3 years to 7 years, 3 months. Though separate and distinct from the WISC-III (discussed below), it is similar in form and content. The WPPSI-R is considered a downward extension of the WISC-III. These two tests overlap between the ages of 6 and 7 years, 3 months. The WPPSI-R has a mean of 100 and standard deviation of 15, with scaled scores for each subtest having a mean of 10 and a standard deviation of 3. It contains 12 subtests organized into one of two major areas: the Verbal Scale includes Information, Similarities, Arithmetic, Vocabulary, Comprehension, and Sentences (optional) subtests; the Performance Scale includes Picture Completion, Geometric Design, Block Design, Mazes, Object Assembly, and Animal Pegs (optional) subtests. The WPPSI contains 9 subtests similar to those included in the WISC-III (Information, Vocabulary, Arithmetic,

Similarities, Comprehension, Picture Completion, Mazes, Block Design, and Object Assembly) and 3 unique subtests (Sentences, Animal Pegs, and Geometric Design). Three separate IQ scores can be obtained: Verbal Scale IQ, Performance Scale IQ, and Full Scale IQ. The WPPSI-R was standardized on 1,700 children equally divided by gender and stratified to match the 1986 U.S. census data. This instrument cannot be used with severely disabled children (IQ's below 40) and, with younger children, may need to be administered over two sessions due to the length of time required to complete the assessment.

*Wechsler Intelligence Scale for Children-III (WISC-III)* (Wechsler, 1991): The WISC-III can be utilized for children ranging in age from 6 years through 16 years of age. It is the middle childhood to middle adolescence version of the Wechsler Scale series. It contains 13 subtests organized into two major areas: the Verbal Scale includes Information, Similarities, Arithmetic, Vocabulary, Comprehension, and Digit Span (optional) subtests; the Performance Scale includes Picture Completion, Picture Arrangement, Block Design, Object Assembly, Coding, and the optional subtests of Mazes, and Symbol Search. Three separate IQ scores can be obtained: Verbal Scale IQ, Performance Scale IQ, and Full Scale IQ. Each of these separate IQ's are standard scores with a mean of 100 and a standard deviation of 15, with scaled scores for each subtest having a mean of 10 and a standard deviation of 3. The WISC-III was standardized on a sample of 2,200 American children selected as representative of the population on the basis of 1988 U.S. census data.

*Wechsler Adult Intelligence Scale - Revised (WAIS-R)* (Wechsler, 1981): The WAIS-R covers an age range of 16 years, 0 months to 74 years, 11 months. The revised version contains about 80% of the original WAIS and was modified mainly due to cultural considerations. There are 11 subtests: Verbal Scale - Information, Similarities, Arithmetic, Vocabulary, Comprehension, and Digit Span; Performance Scale - Picture Completion, Picture Arrangement, Block

Design, Object Assembly, and Digit Symbol. The WAIS-R was standardized in the 1970's on a sample of 1,880 white and non-white Americans equally divided among gender. The WAIS-R has a mean of 100 and a standard deviation of 15 with the scaled scores for each subtest having a mean of 10 and a standard deviation of 3.

*Stanford-Binet: Fourth Edition (SB: FE)* (Thorndike, Hagen, & Sattler, 1986): The SB: FE is appropriate for use on individuals ranging in age from 2 to 23. It is comprised of 15 subtests, though only 6 (Vocabulary, Comprehension, Pattern Analysis, Quantitative, Bead Memory, and Memory for Sentences) are used in all age groups. The other 9 subtests (Picture Absurdities, Paper Folding and Cutting, Copying, Repeating Digits, Similarities, Form-Board Items, Memory for Objects, Number Series, and Equation Building) are administered on the basis of age. Unlike previous editions, the SB: FE uses a point scale similar to that of the Wechsler Scales, is more culturally sensitive, and includes some new items in the areas of memory for objects, number series, and equation building.

Once administered, the SB: FE yields three types of scores: age scores (or scaled scores), area scores (general intelligence, crystallized intelligence and short-term memory, specific factors, and specific factors plus short-term memory), and a Composite Score (similar to the Full-Scale IQ of the Wechsler). The SB: FE Composite Score has a mean of 100 and a standard deviation of 16 (unlike the Wechsler's standard deviation of 15).

*Overlap between the WISC-III and the Stanford-Binet: Fourth Edition:* The WISC-III is appropriate between the ages of 6-16, while the Stanford-Binet: Fourth Edition is appropriate between the ages of 2 and 23. While the child is between 6 and 16, either test is appropriate. Correlations range from .66 to .83 between the WISC-R Full Scale IQ and the Fourth Edition composite. Results from Thorndike, Hagen, and Sattler (1986) show that while the two tests yield approximately equal

scores, they are not interchangeable. This is partly due to the fact that they operate on different standard deviations (Sattler, 1992).

*Overlap between the WAIS-R and the Stanford-Binet: Fourth Edition:* Results for individuals with and without mental retardation are similar in that the WAIS-R yields higher scores than the Stanford-Binet Fourth Edition.

*Special Note: Assessment Tools for Individuals with Mental Retardation.* The Stanford-Binet: Fourth Edition and the Wechsler Scales are useful instruments in assessing mild mental retardation; however, neither is designed to test individuals with severe/profound mental retardation. In addition, due to the high floor on the Wechsler Scales the publisher recommends that a child obtain raw score credit in at least 3 subtests of the Verbal Scale and the Performance Scale before assuming they provide useful information. Raw score for 6 subtests, 3 Verbal and 3 Performance are recommended for a valid Full Scale IQ.

*McCarthy Scales of Children's Abilities* (McCarthy, 1972): The McCarthy Scales can be used with children between the ages of 2 ½ years and 8 ½ years. It contains six scales: Verbal Scale, Perceptual-Performance Scale, Quantitative Scale, Memory Scale, Motor Scale, and General Cognitive Scale. In addition to yielding a General Cognitive Index (GCI), the McCarthy Scales provide several ability profiles (verbal, non-verbal reasoning, number aptitude, short-term memory, and coordination). The overall GCI has a mean of 100 and a standard deviation of 16 and is an estimate of the child's ability to apply accumulated knowledge to the tasks in the scales. The ability profiles, in particular, make the McCarthy Scales useful for assessing young children with learning problems. The GCI is not interchangeable with the IQ score rendered by the Wechsler Scales; therefore, caution is advised in making placement decisions based on the GCI, especially in the case of children with mental retardation (Sattler, 1992).

## AREAS OF FOCUS AND SPECIAL ATTENTION

### A. Early intervention, assessment and Medical Treatment

- i) **Prevention:** The prevention of disabilities, to a large extent, is the domain of the medical profession, family counselors, psychologists and social workers and has its basis in research and training within those disciplines. However, educational services have a role to play through the provision of courses of study in schools/colleges for students in the areas of health, education and child development. This would supplement information provided to the families and could improve their knowledge and skills for prevention of disabilities.
- ii) **Detection:** A reliable and accessible diagnostic system is a prerequisite for the development of preventive and intervention strategies. Children who have been diagnosed within the first few weeks or months of life, given appropriate intervention and family support, very frequently achieve more than children whose diagnosis has been delayed and where professional intervention or family has been uncertain.
- iii) **Intervention:** Referral to a multi-professional team at district level will be essential for those children who have moderate or severe levels of impairment. The composition of these teams will reflect a concern for children in relevant developmental and health areas.

- iv) **Counseling:** It is an area which cuts across a number of concerned disciplines such as anthropology, sociology, genetics, psychology, social work, religious instructions etc.
- v) **Genetic Counseling:** There is need to make knowledge about genetic transference of disabilities available to the general public, in particular to parents and prospective parents. This responsibility is difficult to pin point in respect of the various government agencies as it is to be shared by a number of departments such as Ministry of Health and Ministry of Women Development, Social Welfare and Special Education at the Federal level.
- vi) **Family Guidance:** The provision of family based guidance about children at early age level requires a combination of teaching competence and skills essential for social work. A systematic training program for the parents of children with disabilities and for the children themselves provides excellent opportunities for early learning by the child. It also provides skills and confidence for parents who may be anxious and need to develop skills for meeting the special needs of children with disabilities.

## **B) Education and Training:**

- i) **Education:** Starting from a scratch, Pakistan has made significant progress in all relevant areas since the establishment of Directorate General of Special Education (DGSE) and National Trust for the Disabled (NTD) at the federal level in eighties. The provincial governments and NGOs joined the movement and initiated special projects. At the International level, the movement towards making special education an integral part of education has been gaining ground. Integration of children with disability in normal system of education shall therefore be promoted at all levels.

ii) **Training:** Training programs for teachers and social welfare workers and the course content at postgraduate level shall include an element of awareness training in disabilities from the perspective of that profession and its role related to persons with disabilities. The existing system of postgraduate training in special education at the university level will be further strengthened and expanded. The training institutes like National Institute of Special Education (NISE) will further strengthen their program of Teacher Training and Research, for improved service delivery.

Training of doctors, pediatricians and other related specialists in the diagnosis of disabilities will be arranged at medical colleges or at relevant departments at the university level, in order to build up a well qualified professional team.

The number of training institutions available for occupational therapy and physiotherapy will be increased along with training centers for speech therapists and other relevant professionals. Training facilities at National Institute of Handicapped (NIH) and other institutions will be continued to be supported through the collaboration of federal government, provincial governments, district governments and international donor agencies.

iii) **Integration and mainstreaming:** Recognizing the need for affording the education facilities to a maximum number of children with disabilities, their integration shall be ensured by adopting the following measure:-

- provision of special aids and equipment,
- alignment of policies between the Federal government, the provincial governments and the district governments at the level of relevant ministries and departments,

- changes in curriculum in collaboration with relevant departments, agencies.
- Provision of specialized aids and equipment.

### C. Vocational Training, Employment and Rehabilitation

i. **Vocational Training:** Vocational training facilities at present are very limited to meet the requirements of persons with disabilities in both private and public sectors. The following measures will be adopted and promoted for further extension of these facilities to a larger segment of persons with disabilities:

- a) establishment of sheltered and integrated workshops at provincial level,
- b) establishment of vocational training centers at district level,
- c) utilization of vocational training programs administered by the federal, provincial, district governments and by private agencies, linkages with relevant government and non-government establishments for the utilization of their facilities by persons with disabilities.

Existing network of over 100 training institutes, established under vocational training system, will be utilized by keeping a provision of 5% seats for persons with disabilities in each Vocational Training Unit.

ii. **Use of information technology:** Information technology has the potential for multifarious uses for and by persons with disability. for the hearing impaired ,it can provide direct access to visual images and sources.

of information and means of instant communication. With additional gadgets for sound production and Braille printing, it can be at the service of the visually handicapped persons. It can be used by persons with hearing disability and solve speech problems as means of communication. It has been used for speech training of persons with mental retardation through relevant games and exercises. Use of persons with disabilities will be promoted in the federal and provincial government special education centers. Private sector will be involved in this system along with the public sector. Options open for the general public in this fast expanding field, will be made available to persons with disabilities.

- iii. **Assistive technology:** Assistive technology plays an important role in rehabilitating persons with disabilities. By using this modern technology these persons can perform in a better way. Special attention will be given to the development of assistive technology with the involvement of relevant organizations, particularly in the services available in the country in this area shall be prepared for facility of the persons with disabilities and for others interested.
- iv. **Outreach program:** The outreach approach involves identification of children with disabilities, assessment of their special needs and training of their family members at their homes. This model will be promoted in the private sector through the provision of training facilities for staff involved in outreach programs and incentives to NGOs. Supportive agencies such as Pakistan Bait-ul-

Mal and Central Zakat Administration along with local bodies, will be encouraged to provide matching financial assistance for such programs.

- v. **Employment:** Pakistan joined the select group of countries, which has not only ratified ILO Convention 159, but have also taken active legal steps to introduce legislation which lays down quota for the employment of persons with disabilities. Disabled Persons (Employment & Rehabilitation) Ordinance, 1981, reserves one percent quota for persons with disabilities. This Ordinance is in the process of being amended to increase the quota from 1% to 2%. The penalty clauses will also be amended to make its implementation more effective. It will also be ensured that the National Policy and all future modifications of it, adhere to the principles laid down in the relevant articles of the Convention 159, which deal with vocational rehabilitation and employment of persons with disabilities.
- vi. **Sheltered/support employment:** In view of minimal opportunities for employment in the open market, alternate arrangements for gainful engagement of disabled persons will be made through the establishment of sheltered workshops or supported employment. Arrangements for establishing units of sheltered or supported employment will be made as part of larger industrial units or as independent establishments.
- vii. **Self-employment:** Special schemes will be launched and existing programs strengthened in the area of self-employment. Agencies like Pakistan Bait-ul-Mal,

Central Zakat Administration, Kush Hali Bank, and National and International Organizations will also be associated to provide financial support through micro-credit schemes, for such programs.

The strength inherent in the community and the families as a resource for vocational rehabilitation of persons with disabilities shall be utilized to the maximum to attain the goals of self-employment. The programs like "Vocational Rehabilitation and Employment of Disabled Persons with Community Participation (VREDP)" shall be replicated in the urban and semi-urban areas for the benefit of persons with disabilities.

- viii. **Incentives to employers:** Enterprises employing workers with disabilities will be given incentives financial assistance and exclusive contracts or priority production rights, as part of the policy to promote gainful employment of persons with disability. Employers will be encouraged to adopt measures for the use of new technologies and the development and production of assistive devices, tools and equipment, to facilitate access for persons with disability to the open market to enable them to gain and maintain employment.

#### **D. Research and Development:**

Both academic and applied research aimed at practical outcome for the ultimate benefit for persons (children and adults) with disabilities, will be encouraged both at the federal and provincial levels. Efforts will be made to enlist the interest and

support of the universities and other organizations particularly in the areas of medicine, social work, psychology, vocational training, engineering.

#### **E. Advocacy and Mass Awareness:**

All possible channels, at community as well as media level, will be utilized to create public awareness about the nature and types of disabilities and the need for community support for the identification as well as rehabilitation. The mosques and other places of congregation will also be utilized as part of the awareness campaign.

The public attitude plays an important role for persons with disabilities to function as fully participating members of society. This is a long process and can only be achieved through constant exposure to positive images of the persons with disabilities and by the projection of their success stories through mass media. The community as a whole must ensure that attention is given, not only to the issues of services planning, but also to the details of access to public buildings, transport and other facilities. The electronic media all over the world has played a significant role in creating awareness regarding the contribution that communities can play for the welfare of persons with disabilities. This will be given special attention by involving television and radio channels in this process through their management, writers and producers.

National level workshops will be organized in this respect in collaboration with PTV and representatives of other sectors of media.

#### **F. Sports and Recreation:**

Provision of appropriately designed sports and recreational facilities for children with disabilities and adults would be undertaken in collaboration with all public and private authorities. Such facilities would, wherever possible, be encouraged within general schemes and will not be segregated as far as possible.

Each district/local authority shall ensure that budgetary provisions exist which will enable groups of persons with disabilities to establish clubs for sports and recreation and shall provide appropriate premises free of rental and standing charges for utilities.

#### **G. Design of Buildings, Parks and Public Places:**

In order to ensure safe and easy access of persons with disabilities in public places/building codes of practice for the design of new public buildings and for the recreation of existing premises are will be prepared and issued with the Pakistan Engineering Council (PEC). Design manuals for public buildings will be prepared by the Ministry of Women Development, social Welfare and Special Education, which will provide specifications for such aspects of those buildings which are used by persons with disabilities such as ramps, lifts, toilets etc. Accessibility to other buildings of public use also requires special designing to facilitate easy approach for persons with disabilities.

#### **H. Institutional Arrangement/Mechanism:**

- i) **Role of the Federal Government:** The role of Federal Government is important in meeting the needs of the persons with disabilities at national level. The present level of support provided by the federal government for efforts in the field of education and rehabilitation of person with disabilities shall be enhanced. Joint effort of the concerned Ministries like Education, Health, Labour and Manpower and Sports and Culture etc. in addition to the Ministry of Women Development, Social Welfare and Special Education shall be ensured for fulfilling the objectives, laid down in this policy.

It is essential that a workable system is developed for inter-ministerial sensitization and collaboration to extract maximum mileage for the benefit of persons with disabilities. One of the areas for collaboration is

the budgetary provision and its utilization for the benefit of persons with disabilities in areas falling under the operational jurisdiction of various ministries/departments.

### **Other Assessment Tools**

*Peabody Picture Vocabulary Test - Revised (PPVT-R)* (Dunn & Dunn, 1981): The PPVT-R is appropriate for individuals between the ages of 2½ and adulthood and measures receptive knowledge of vocabulary. It is a multiple choice test requiring only a pointing response and no reading ability, thus making it useful for hearing individuals with a wide range of abilities, particularly children with language based disabilities. The revised edition is more sensitive to gender-based stereotypes and cultural issues; in fact only 37% of the original items were retained. The PPVT-R has two forms, L and M, with 175 plates in each form in ascending order of difficulty. Each plate consists of four clearly drawn pictures, one of which is the correct response to the word given by the experimenter. Standard scores have a mean of 100 with a standard deviation of 15. The PPVT-R was standardized on a national sample of 4,200 children (2½ - 18) and 828 adults (19 - 40) equally divided among gender and based on 1970 U.S. census data. The PPVT-R was designed to assess breadth of receptive vocabulary and not as a screening tool for measuring intellectual level of functioning. PPVT-R scores are not interchangeable with IQ scores obtained via the Stanford-Binet: Fourth Edition or the Wechsler Tests.

*Columbia Mental Maturity Scale*: The Columbia Mental Maturity Scale (Burgemeister, Blum, & Lorge, 1972) is a test of general reasoning ability that can be used with children who have significant physical limitations. It is appropriate for children between the ages of 3 ½ years and 9 years, 11 months. The Columbia has a mean of 100, a standard deviation of 16, and can be interpreted using age equivalents. When used in conjunction with the Peabody Picture Vocabulary Test

- Revised, it can provide reasonably accurate cognitive status information comparable to the more common intelligence tests.

*Leiter International Performance Scale:* The Leiter International Performance Scale (Leiter, 1948) is a nonverbal assessment of intelligence. Although the norms are dated, it provides useful information about the cognitive status of children with hearing impairments or severe language disabilities. It can be used with children aged 2 through adults. It is currently under revision and will likely be a useful tool in the future (Roid & Miller, 1997).

## **Services/Supports for Special Children**

### **What does the term "supports" mean?**

The concept of supports, as described by AAMR, refers to certain resources and strategies provided to persons with mental retardation that enhance their independence/interdependence, productivity, community integration, and satisfaction. These supports can come from technology, individuals, and agencies or service providers. Supports can be grouped into eight types of function: (1) befriending, (2) financial planning, (3) employee assistance, (4) behavioral support, (5) in-home living assistance, (6) community access and use, (7) health assistance, (8) teaching (Schalock et al., 1994).

The AAMR concept of supports includes assigning one of four levels of intensity to each support: (1) intermittent, or "as needed," which are seen as short-term supports, such as during an acute medical crisis; (2) limited, which are those supports needed regularly, but for a short period of time, such as employee assistance to remediate a job-related skill deficit; (3) extensive, seen as ongoing and regular, such as long-term home living support; (4) pervasive, viewed as constant and potentially life-sustaining, such as attendant care, skilled medical care, or help with taking medications.

The current AAMR definition involves a three-step procedure for diagnosing, classifying, and determining the needed supports of an individual with mental retardation: (1) determine eligibility for supports (IQ 70-75 or below, significant disabilities in two or more adaptive skill areas, age of onset below 18); (2) identify strengths and weaknesses and the need for support across the four dimensions: intellectual functioning and adaptive skills; psychological/emotional considerations; physical/health/etiological considerations; and environmental considerations; (3) identify the kind and intensities of supports needed for each of the four dimensions.

### **What are supports?**

The concept of supports originated about 15 years ago and it has revolutionized the way habilitation and education services are provided to persons with mental retardation. Rather than mold individuals into pre-existing diagnostic categories and force them into existing models of service, the supports approach evaluates the specific needs of the individual and then suggests strategies, services and supports that will optimize individual functioning. The supports approach also recognizes that individual needs and circumstances will change over time. Supports were an innovative aspect of the 1992 AAMR manual and they remain critical in the 2002 system. In 2002, they have been dramatically expanded and improved to reflect significant progress over the last decade.

Supports are defined as the resources and individual strategies necessary to promote the development, education, interests, and personal well-being of a person with mental retardation. Supports can be provided by a parent, friend, teacher, psychologist, doctor or by any appropriate person or agency.

### **Why are supports important?**

Providing individualized supports can improve personal functioning, promote self-determination and societal inclusion, and improve personal well-being of a person

with mental retardation. Focusing on supports as the way to improve education, employment, recreation, and living environments is an important part of person-centered approaches to providing supports to people with mental retardation.

### **How do you determine what supports are needed?**

AAMR recommends that an individual's need for supports be analyzed in at least nine key areas such as human development, teaching and education, home living, community living, employment, health and safety, behavior, social, and protection and advocacy.

### **How is mental retardation diagnosed?**

Mental retardation is formally diagnosed by professional assessment of *intelligence* and *adaptive behavior*. Intelligence is the ability of a person to learn, think, solve problems, and make sense of the world. Intellectual functioning, or IQ, is usually measured by a test called an IQ test. The average score is 100. People scoring below 75 are often -- but not always -- mentally retarded. Since factors other than mental ability (depression, anxiety, lack of adequate effort, etc) can yield low IQ scores, it is important for the evaluator to rule them out prior to concluding that measured intelligence is "significantly below average". Adaptive behavior, or adaptive functioning refers to the skills needed to live independently (or at the minimally acceptable level for age). To assess adaptive behavior, professionals compare the functional abilities of a child to those of other children of similar age. To measure adaptive behavior, professionals use instruments that are actually structured interviews, with which they systematically elicit information about the person's functioning in the community from someone that knows them well. There are many adaptive behavior scales, and accurate assessment of the quality of someone's adaptive behavior requires clinical judgement as well. Examples of the kinds of behaviors that are assessed by

adaptive behavior scales Certain skills are important to adaptive behavior. These are:

**1. Daily living skills**

As getting dressed, going to the bathroom, and feeding one's self

**2. Communication skills**

Such as understanding what is said and being able to answer;

**3. Social skills**

With peers, members, adults, and others.

Another evaluation technique is the job tryout or exploratory work situation. This method consists of the use of workstations either within the habilitation center or in business and industry. Vocational training is intended to develop skills that will allow the handicapped person to be gainfully employed despite his handicap.

**Vocational Training**

Vocational training should be practical, which the trainee can learn to a reasonable standard of perfection. Some vocations, depending upon whether the retarded is a boy or girl, which meet the requirements, are easy and economical to teach, keeping in mind the chronological age, physical capability, and mental development of the retardate some trainings are:

- Laundry
- Cooking
- Household work: Sweeping, dusting, scrubbing, polishing dishwashing, setting tables, making beds and other odds and ends of duties connected with house or a cafeteria.
- Sewing
- Embroidery
- Painting
- Cane work

- Wood work
- Weaving

Other vocations can be picked up and introduced from every day life, depending upon available facilities of instructions and practical possibilities of application of employment.

Null And Hardy (1972) Distinguish among four types of Training Methods

1. Personal adjustment training is designed to develop proper work habits attitudes, and behaviors to help the client understanding and get a long in a work situation.
2. Prevocational training provides background and supplementary knowledge and skills requisite for an occupation.
3. Compensatory skill training provides specific skills needed to enter the labor market but not necessarily directly related to a specific occupation, speech reading for deaf people is one illustration.
4. Vocational training provides specific knowledge and skills necessary for performance within a given occupation. Training methods may involve didactic instruction as well as on the job and apprenticeship training.

The choice of vocational training courses for the mentally retarded requires a knowledge of careers suitable for varying levels of ability and skills as well as knowledge of the current labor market and local employment conditions that would make a specific occupation feasible (Marvin Rosen 1977).

In considering the overall concept of rehabilitation as it applies to the mentally retarded, certain basic factors need to be given attention. Retardation of the mentally retarded does not seek the restoration.

### **Background Information on Special Education in Pakistan**

The need to educate its disabled population has gained increasing recognition in Pakistan in the last two decades. Interest in the field was aroused by the International Year for Disabled Persons (1981), and by the United Nations Declaration of 1983-92 as the Decade of the Disabled. In the 1980s, the Government of Pakistan undertook a crash programme of expansion of special educational provision, thus improving both the quantity and quality of existing facilities. However, the continuing absence of any form of legislation for the education of children with special educational needs, continues to deny the great majority of these children the right to education.

### **The Development of Education, and Special Education in Pakistan**

Despite an unprecedented increase in primary education the Government has been unable to achieve its target of providing universal primary education. Primary education is even now available to only 60 percent of children (Pakistan Planning Commission 1988). Plans for providing universal free and primary education had to be shelved because of the huge expenditure involved, which the national economy was unable to sustain (Dani 1986). Unfortunately there has been no significant change in this unhappy state of affairs in the 1990s. Thompson (1998) indicates that the drop out rate before completion of primary education is very high, and nearly seven million children remain out of school.

An experience of this kind is not unique to Pakistan. Haddad (1990) cites evidence to show that this situation is found to prevail in other developing nations. Writing on the proceedings of the World Conference on Education for All, he states that the phenomenal expansion of the national educational systems since the 1950s has continually increased the number and proportion

of children in school. However, the absolute number of out-of-school children has at the same time increased dramatically.

The responsibility of the Government to educate its handicapped pupils was recognised in the Commission on National Education (Pakistan Ministry of Education 1959). But the proposal to provide education for these children was not made until the Education Policy 1972-1980 (Dani 1986), and in the Fifth Five Year Plan (Pakistan Planning Commission 1978) a modest sum was allocated to special education.

In the 1980s, due to the efforts of the late President Zia-ul-Haq, much greater government involvement was witnessed and increased budgetary provision for special education (though still inadequate) was made. During the Sixth Plan (1983-1988), the social welfare programme concentrated on strengthening existing institutions of social welfare and of special education, both government and non-government. In order to overcome organisational setbacks, a Federal Directorate General of Special Education with provincial counterparts was set up in 1985, and the first National Policy for Rehabilitation of the Disabled was formulated in 1986.

Some of the difficulties experienced in the Sixth National Plan in implementing the National Policy were insufficient budgetary provisions, lack of trained personnel, and shortage of service centres (Pakistan Planning Commission 1988).

The Economic Survey (Pakistan Planning and Development Division 1991-92) states that the major emphasis during that year had been on improving provision, enhancing the performance of the executing agencies, and strengthening and consolidating social welfare and rehabilitative services. (For a more detailed account of special education in Pakistan see Lari 1996a, b).

## **National Policy for Rehabilitation of the Disabled**

The declaration by the United Nations of 1983-1992 as the Decade of the Disabled brought into focus the long existing need to formulate a national strategy to tackle the problems of the disabled and handicapped of all categories and descriptions. The National Policy for Rehabilitation of the Disabled was thus conceived in December 1986 by the Ministry of Health, Special Education and Social Welfare, and this was in fact the first policy on special education in Pakistan.

The National Policy determines the philosophy of special education in Pakistan, and outlines goals in the areas of assessment and intervention for special educational needs, the curriculum in special schools, and teacher training programmes in special education. (See also Lari 1997, 2000).

Educational provision for children with special educational needs is the responsibility of the Ministry of Education in Punjab and Sindh. Interestingly, in Baluchistan and in NWFP this portfolio is held by the Ministry of Women Development, Social Welfare and Special Education.

## **Special Education In Pakistan**

In Pakistan it is generally acknowledged that the development of special education institutions and other project for the welfare of the disabled in Pakistan during the decade of disabled (1983-1992) has been rapid and the system evolved could be presented as model for developing countries. A very significant factor in this phenomenal growth has been a sense of collaboration and partnership between public and the private sectors. The Federal Government in 1985 established the Directorate General of Special Education for the formulation and implementation of National Policy in the fields of Welfare of the disabled, which helped to speed up the process as catalytic agent. There are 52 special education center throughout

the country which provides technical and financial support by the help of federal Govt. Pakistan's efforts were appreciated at the international and regional level in the conferences and seminars held for the evaluation of the progress during the decade.

The years 1993 was declared as SAARC year of the disabled and because of its pioneering work in the field a number of activities at the national and the regional level were organized by Pakistan, which included a National Conference and a SAARC Ministerial level conference at Islamabad.

The system of special education and programmes, for the welfare of the disabled also seem to have reached a stage where of its current status will be helpful in determining the important directions.

#### **Disability Population Analysis National Census (1998)**

1.	Total Population	132352279
2.	Population of Disabled Persons	3293155

#### **Population Disability-Wise**

S.No.	Disability	%
1.	Blind	08.06
2.	Hearing Impaired	07.40
3.	Physically Handicapped	19.00
4.	Mentally Retarded & Insane	14.00
5.	Having more than one disability	08.21
6.	Other (Not classified)	43.33
<b>G. Total =</b>		<b>100%</b>

#### **Disability Population Analysis National Census (1998)**

### No. Of Centers For Special Education

PROVINCE	V.1	H.1	M.R	P.H	TOTAL
Punjab	13	27	10	3	53
Sindh	12	16	12	6	48
NWFP	4	7	6	5	22
Balochistan	1	1	1	1	4
Total	30	81	29	17	127

The present data collected by NISE in 1992 shows that there has been significant increase in the total number, which has increased from 127 to 282. The total number of beneficiaries have also shown an increase of more than 100% i.e. from 8154 to 18254 (NISE. 1994).

**Distribution Of Special Education Centers In Pakistan (Working Under Dgse, Islamabad)**

Area	HIC	VHC	PHC	MRC	VTCD	VRED P	Total
Punjab	05	05	04	05	01	01	21
Sindh	01	03	02	02	01	01	10
NWFP	02	02	02	02	01	-	09
Baluchista n	01	-	01	01	01	-	04
N. Areas	01	-	-	-	-	-	01
Islamabad	01	01	01	01	01	01	06
AJK	-	-	01	-	-	-	01
Total	11	11	11	11	05	03	52

It is therefore appropriate to say that the system of special education in Pakistan has gradually become more sensitive to the nature of disabilities and open to the creation of new diagnostic

ice categories.

Efforts are currently being made for disable in Islamabad/Rawalpindi area by NISE (National Institute of Special Education) in collaboration with Federal Directorate of Education and UNICEF. This is considered as an important area for the expansion of Education for the disabled children in the future. The total number of the disabled children in Pakistan, according to the WHO estimates of 10% Population, comes to over 12 million. A developing country like Pakistan cannot possibly bear the expenditure of providing special education schools and

centers, particularly for children belonging to the rural populations and small towns.

It is estimated that approximately three percent (3%) of the population is affected with mental retardation in some measure in developed countries like U.S.A., U.K., and elsewhere. In Pakistan the possibility is of a higher percentage because of ignorance, prevalence of disease, unhygienic living conditions and under-nourishment. Even at the given rate of three percent (3%) the number of retarded persons is phenomenal, e.g.

- Karachi with an estimated population of 8,000,000 (m) is likely to have no less than: 240,000 retarded persons.
- Pakistan with an estimated population of 100 million is likely to have: 3,000,000 retarded persons. (Muslim, 1993).

Presently, there is a visible change in attitudes, which is taking place very rapidly due to the modernization and more humanistic concern towards human welfare. Every civilized nation of the world is catering services for the needy with in the frame of their socio-cultural and economic set up.

During independence country was facing number of problem due to which less attention was given to special people. Most of the people of Pakistan are poor, low health facilities, lack of education and awareness. In such a miserable situation they are unable to get the desired facilities in the pre-natal phase of pregnancy.

Tauseef Ahmad (1995) was of the opinion that poverty is a major cause of disabilities. However progress in social welfare of a society can be gauged from how well persons with physical and psychological disabilities are able to be rehabilitated so that they can become productive members of the population. It was for the purpose of drawing attention to this aspect of population development that Governments in the ESCAP region proclaimed the period 1993 to 2002 as the

Asia and Pacific Decade of disabled persons that action was followed later in 1992 by the proclamation on the full participation and Equality of people with disabilities in the Asia and Pacific Region, and the adoption of a related Agenda for action (ESCAP, 1994a). These powerful mandates are aimed at helping developing countries such as Pakistan to adopt policy initiatives and program actions that would improve the broad living conditions of the proportion of the total population that is disabled. It is considered that if the behavior of the society is negative, it will be difficult for that society to focus on the person and the human resource, whose abilities can be developed to enable him or her to become a productive partner in the national development process. Removal of the stigma attached to deformities is another policy concern in Pakistan.

In 1986 in Meu Hospital Lahore (Pakistan) rehabilitation Section for the physically handicaps was started. It was the first complete planned section for the handicaps. Later three more rehabilitation centers were opened in:

- *Rawalpindi:* Armed Forces institute for rehabilitation of handicaps.
- *Karachi:* Jinnah Post-Graduate Medical Institute of handicaps.
- *Islamabad:* National Institute of Handicapped.

These rehabilitation centers provide many up to date trainings and skills to the handicapped (Sihat aur Sarifeen. 2002).

The main purpose of rehabilitation is to help disabled individuals to the maximum. The society for children in need of special attention was formed in 1960. It was the first institute in Pakistan, today there are a number of institutions in all major cities. Public social welfare department and government is very much conscious for this problem.<sup>3</sup>

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<sup>3</sup> Sahat aur Sarafeen. Monthly Journal, November/December, 6<sup>th</sup> Vol. Islamabad. 2002.

Services for mentally retarded are essentially the same as services for normal children and adults: educational, vocational, health and medical care, social, psychological and protective services. This group requires these services in a modified form i.e., some require additional care and protection, and even few special people needs on a life long services. Attitudes of normal people are changing during the last two decades. The current thinking has generated awareness in planners, professionals, politicians, and general people with intellectual impairment have a right to live and participate fully in community.

When the professionals like doctors, social workers, nurse, teacher and psychologist plan services for the mentally retarded the action plan should be formed jointly. They should produce a co-ordinate program designed around individual needs and preferences, building on the strengths of the client. The planned program must consider the normal daily life style of the career and the client. For this purpose the classification of mentally retarded is very important, because it is only then possible to plan the services to be provided accordingly.

A growing trend in services to the mentally retarded is normalization, a concept that was developed and applied in Scandinavian countries during the late 1960s. This concept advocates that the mentally retarded persons be allowed to act in as normal manner as possible, given his limitations. It is preferable for the mentally retarded to share the facilities of normal. Another part of the concept is that retarded people should be trained to behave as normally as other people in the community do, so they will not be seen as deviant.

Parents may find for caring the profoundly/severely or even moderately retarded child. Many such children have physical complications that require medical care too. Training the child may require specialized and prolonged facilities, close supervision. The parents having knowledge about child's behavior and activities are the best judge to decide that which institution will be the best to serve the child's needs. Some institutions offer good custodial care, specialized medical and

educational programs geared to the needs of the child however most children end-up in an institution with a limited staff and with out modern educational and medical facilities. Though such institutions may have some habilitation, rehabilitation, clinical and educational programs, but these are not likely to be very effective in dealing with the child's needs and in teaching coping skills.

Some researchers and theoreticians voice the even stronger criticism that institutions are dehumanizing and destructive to the personality of their inmates. Under institutional conditions, the intellectual functions of mentally retarded individual tend to decline.

Comparisons of institutions and home environment are more favourable to mental development. Home care does have advantages, the mentally retarded child is far more likely to receive individual attention, love and stimulation in his home where family members interact with him, show their interest and concern for him and encourage him to make use of his capacities. Parents often feel more at ease with themselves and less guilt-ridden because they did not get rid of the defective child. Siblings usually love and take responsibility for their mentally retarded family member, who thus feels accepted and part of the family group. In such a attention seeking behaviour, the condition for intellectual development are most favorable. The trend today is to encourage families to take care of their own retarded children, if at all possible, at least until school age. The family also need counseling in caring the special groups particulars the retarded children this can done through agencies that provide household help and visits by nurses, teachers, social workers and other specialists who are trained to work with the mentally retarded.

Enola Proctor (1983: 515) proposed new directions of involving parents in making the life of mentally retarded children functional. She pointed out that the social workers can help parents to develop realistically positive expectations towards their children in several ways, which are:

1. Parents should be encouraged to expect their child to learn only one skill or behavior at a time.
2. Parents can be assisted in assessing their child's readiness to learn the identified target skill.
3. Parents should be assisted in identifying and ordering the component sub steps of the task to be achieved.

Exclusive attention to parent's attitude and feelings can equip them with new ways of responding to their children with special needs, particularly with mental deficiencies. Perhaps uniquely parents can help their children to acquire adoptive behaviour, particularly self-help and social skills.

William Schwartz (1976) presented a "Mediating Model" for intervention of individual and social setup, and the relationship between the two. He stressed on intervention to be realistic in terms of attaining goals, while supporting individual strength and encouraging creativity.<sup>4</sup>

If a family feels they are not prepared, either psychologically or for practical reasons, to look after the child another possibility is foster home care. Social workers usually select foster homes carefully and supervise them regularly. Foster home placement has been utilized successfully.

A sheltered workshop is a special vocational center which provides remunerative employment for persons who are so severely handicapped, as to require considerable supervision or whose capacity to work productively outside sheltered workshops is impaired by extensive physical or mental handicaps. In other words, employment is provided in a sheltered setting where work tasks responsibilities, and production are geared to potential of the persons employed in the sheltered workshop. Sheltered workshops may provide vocational, diagnostic, and training

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<sup>4</sup> Differential Diagnosis and Treatment in Social Work.

services in various occupations, e.g. A sheltered workshop might provide services for those who could work only under sheltered work conditions, as well as for those who would benefit from vocational training that would be provided in the workshop.

## **REHABILITATION SERVICES IN PAKISTAN**

Pakistan is running training and rehabilitation programs for the last 38 years. In Pakistan the total number of special centers for the special children are 132, in which 53 are from Federal Govt. and 79 are from Provincial Govt.

The basic ingredients of any education and training program for the Mental Retardation are:

- i) Love and affection and due attention.
- ii) Commitment to help the Mentally Retarded population.
- iii) Patience, empathy and perseverance.

Short courses which are offered from the Ministry of Social Welfare and special Education. 3 months special education course Matric and Graduates, first class higher 2<sup>nd</sup> class and merit can apply. The quota for employment in Pakistan is raised from 1% to 2%.

Thus habilitation took and added dimension in the 1960s and 1970s. a direction that represented, a departure even from the optimism of the early educators of the retarded, the concept of normalization expressed by Nirjae (1969) and others demanded that the mentally retarded be provided their full right and benefits as citizens.

In the case of the mentally retarded and other developmental disabilities, the rehabilitation concept requires stretching to assume new dimension, the process of vocational habilitation has assumed different meaning in different settings.

The work adjustment phase of vocational habilitations refers to the treatment process designed to improve work behaviors. Work adjustment is the implementation of a vocational evaluation of success or failure in meeting criteria of vocational compliance established by this plan, and the decision to terminate the treatment plan, vocational and work evaluations.<sup>5</sup>

### **Half-Way Houses**

Half way houses are designed principally for the purpose of aiding institutionalized residents who have no active family resources to make the step back into the community. The half way house, typically, is located in the community near employment resources. The advantage of the half way house is that it provides opportunities for continuous guidance and supervision. It also serves to assist the resident to get adjusted to community life and become established as an active community member, a year or two, the resident leaves the half way house to find his own place of lodging.

### **Nursing Care**

School nurses are the primary source of nursing care for retarded children. Each handicapped child is to be placed in the "last restrictive environment". Nurse helps the parents to accept child's behaviour.

### **Occupational Therapy**

Occupational therapy is the exercise of skill, care, and judgment in assessing the degree of a person's mental disorder and or physical disability and treating such a person accordingly by selecting and utilizing appropriate activities of the person's normal pattern of life.

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<sup>5</sup>B. Nirje, . 1969, the normalization Principle and its human management implications. In M. Rosen, G. R. Clark and M. S. Kivitz (eds). *The history of mental retardation: collected papers* pp.361-376. Vol. 2 University Park Press, Baltimore, 1976.

The occupational therapist is a specialist in determining the ability of client, to perform everyday task, appropriate, informal and encourage to concentrate on job. They contribute to the development of basic skills, such as color discrimination, shape recognition and hand-eye coordination.

Traditional occupational therapy treatment methods are:

- *Table – top activities:* Jigsaws, artwork shape, and pasting/matching.
- *Craftwork:* Try or rug making, used mainly for elderly people.
- Pottery and design making.
- Candle making
- Gardening

## THE CURRENT SITUATION IN PAKISTAN

Fifty years is a brief period in the life of a country. Pakistan is still struggling to define its identity as a nation. In this brief period Pakistan has military rule for the third time. Though an Islamic state, Pakistan has had liberal policies towards shaping a female identity and can boast of having elected to office the youngest female Prime Minister ever to rule a Muslim country, or perhaps anywhere in the world.

Pakistan has its share of female professionals: artists, writers, educationists, female ministers of education for the Federal Government and for the Province of Sindh, women representatives in the National Council, and a female representative for human rights at the UN. It is heartening to note that some women overcome obstacles that appear to be insurmountable. These women have a strong determination to succeed, they have endurance and perseverance to stick with what they take on board. Self-discipline is very important too. These are qualities that all women can acquire, and many women with varying degrees of disability have the will to succeed. Personal

social education should be made a necessary part of the curriculum both in and out of school education.

In Pakistan, women's rights including the right to education, are yet to rise to the same level as in the western world. The same is true of the rights of the disabled. Women are campaigning for equal rights in education and in the work place. If Pakistan has a policy of equal opportunities, then this means safeguarding the rights of the individual, the rights of women, and the rights of the disabled.

Psychologists generally agree that the issue of defining one's identity is far more complicated for women, and women's dream is more complex because of the traditional family/career divide (Lari 1994). Women have to face many barriers in achieving their goals and aspirations. For women with disabilities this task is far more difficult. Family support is therefore essential.

Many women are faced with enduring attitudes of prejudice, not only from the wider community, but often from within their own communities and families. They need a great deal of support and encouragement in crossing these barriers. It is far more difficult to achieve for women who are disadvantaged, do not have an adequate education, and are lacking in family support. For them it is a constant struggle against tradition, prejudice and overt sexism. These women stand to benefit tremendously from support and guidance through government policies and organisations designed to help them. We have a social responsibility to offer personal choice to all women, including those with disabilities.

Education can open up minds and provide opportunities, a task that many NGOs are fulfilling. What is needed is positive discrimination for women through government policies, implemented by both government centres and NGOs alike.

It is clear from the data cited by the Planning and Development Division, Government of Pakistan (1996-97), that the enrolment for females is much lower than for males, though enrolment rates for females have risen since 1983-88. The present government has taken some steps to correct this imbalance. Much greater funds have been allocated for the education of girls but this increase is nowhere near being sufficient. It is imperative that female education to those above school age should be provided through non-formal and community based programmes. Scattered individual efforts are laudable but these cannot hope to address the enormity of the problem.

To promote access to classes certain practical considerations must be taken into account. Women's personal and domestic responsibilities have to be recognised and accommodated and support is needed where problems in relation to the domestic or the work situation are identified. The timing of the classes is also an important factor. Provision must fit in with family commitments and creche facilities should be made available.

Further questions arise about the nature of female education. Students should be able to negotiate the content of courses to make it relevant to their experiences and requirements. Access courses providing study skills and computer skills are required. Moreover, women's education has to start with a feminist perspective that recognises the value of life experiences, both personal and collective, to facilitate personal growth. The whole area of personal social development is especially important for women with disabilities in order to promote a positive self-concept by alleviating anxiety and improving confidence in themselves. Having a mentor is of great value. Self-development projects for women with mentoring on offer would be of great value (Lari 1994).

These courses should be free of cost, or cost should be kept at a minimum in order to provide access to all women regardless of their socio-economic background. Such courses would be expensive to run if women in outlying areas are to be reached but investments made are in a worthy cause, which makes it justifiable. Lack of funding makes it a vulnerable area. A concerted effort is required.

Thompson (1998) in an overview of the Provision for Special Educational Needs in Pakistan, states that 'It is important that Federal, Provincial and NGO provision in the field of special educational needs establish links and ensure co-ordination and co-operation of activities' (p.21).

The same report indicates that donor agencies, including UNICEF and the World Bank, discussed the possibility of extending the Social Action Programme to include special education and to identify possible priorities. It is interesting to note the consensus view that future initiatives should focus on gender and disability.

Traditional gender roles are breaking down in Pakistan. More and more women are going out to work, even in fields that were previously considered to be male domains. Women are beginning to evolve a new confidence in their work. Even in the villages, women work side by side with men while successfully running their homes. At the same time though women who choose to stay at home are exercising their right of freedom of choice and can still play an important role by building for the future, for our children are our future.

Women in Pakistan are beginning to challenge the status quo for a brighter future. The media can play a responsible role by raising concerns about discrimination, whether on the basis of gender or disability. It will take many years to implement any real change but many women in Pakistan are

struggling to pave the way for it. Networking is so important in building for the next generation. The fight against stereotypical roles is on. Female qualities need to be valued, both in the work force and in the home. Women must be allowed to integrate without losing their identity. As we step into the 21st century women hope for an egalitarian society worldwide.

## **OVERVIEW OF RECENT DEVELOPMENTS IN INTERNATIONAL AND REGIONAL NORMS AND STANDARDS RELATED TO PERSONS WITH DISABILITY**

**Clinton E. Rapley – Director of Planning Services**  
**Associates for International Management Services**

### **POLICY INSTRUMENTS OF UN GLOBAL PROGRAMME ON DISABILITY**

- *World Programme of Action concerning Disabled Persons*
- Two goals: full participation, and equality
- Three objectives: prevention, rehabilitation and equalization of opportunities
- Findings of fourth review and appraisal (A/58/61/E/2003/5):
  1. Progress on the elaboration of a comprehensive and integrated international instrument on the rights of persons with disabilities in the context of development
  2. Policy priorities for action on equalization of opportunities in the context of development – accessibility; social services and safety nets; and employment and sustainable livelihoods
  3. Progress in reinforcing the disability perspective in technical cooperation activities

4. Progress in data and statistics on disability in mainstream development
  5. Progress in improved planning and coordination of activities of the United Nations system to promote equalization of opportunities
- Report findings and recommendations noted with appreciation by General Assembly resolution 58/132 of 22 December 2003.

#### **POLICY INSTRUMENTS OF GLOBAL PROGRAMME ON DISABILITY**

- Standard Rules on Equalization of Opportunities for Persons with Disabilities
- Proposed supplement: "reaching the most vulnerable"
- Selected topics:
  - Adequate standard of living and poverty alleviation
  - Housing, including the issue of residential institutions
  - Health and medical care
  - Emergency situations
  - Access to the social environment
  - Communications issues
  - Personnel training
  - Gender
  - Children with disabilities and the family
  - Violence and abuse

- o Older persons
- o Development and psychiatric disabilities
- o Invisible disabilities

## **WAY AHEAD CONCERNING NORMS AND STANDARDS RELATED TO DISABILITY**

- Third Committee (Social and humanitarian) of General Assembly at its 59th session will consider report on fourth session of AHC: Report is considered as part of the "human rights" set of agenda items of the Committee, although presentations are made by both Human Rights and Department of Economic and Social Affairs
- Fifth Committee (Administrative and budget) of General Assembly at its 59th session will consider financial implications of recommendations submitted by fourth session of AHC: Main issue before the Committee: how many sessions of AHC and their duration in 2005, and how to pay for this.

## **NATIONAL AND INTERNATIONAL STATISTICS POLICES AND PLANS FOR DISABLED PERSONS**

**Database on prevalence of disability in India, Nepal, Bangladesh, Pakistan, Bhutan, Maldives, and Sri Lanka**

*"Many ESCAP developing and least developed countries and areas do not collect disability data. In the case of those that have done so, the data collected do not reflect the full extent of disability prevalence. This limitation is due in part to the conceptual framework adopted, the scope and coverage of the surveys*

*undertaken, as well as the definitions, classifications and the methodology used for disability data collection."*

Surveys without services followed immediately raises hopes in the community and leads to frustration of stake holders. It costs money to conduct scientific surveys. The precious money is urgently required for rehabilitation services. However there is need for database for planning programs. Many ministries for example in education/health/social welfare use rates/formulas for the calculation of database. Disability sector also needs such a data base.

#### *Purpose of this study*

The magnitude of the problem of disability is vast and its impact is very severe on the individual, families and community.

There are several accepted political goals such as universalization of elementary education, mass literacy programmes, poverty eradication programmes, health for needy people and other developmental programmes.

These are aimed at improving the quality of life of under-privileged groups such as people with disabilities.

India has participated in almost all international conventions and conferences on special need education and has been a signatory to all the important declarations made by UN agencies. Though there are many such declarations and statements issued from time to time since more than two decades, three very important declarations have to be mentioned.

The conventional approaches in rehabilitation such as special schools, social and vocational training centers, special employment schemes, residential schools, hostels etc. are expensive models. It should be important to develop a rehabilitation plan for persons with disabilities aiming at a large coverage with good quality services in a sustainable manner by optimal utilization of existing resources.

It has been half a decade since PEOPLE WITH DISABILITIES (EQUAL OPPORTUNITIES, PROTECTION OF RIGHTS AND FULL PARTICIPATION) ACT 1995 has been passed, yet the concept of rehabilitation services for all differently abled persons has still not taken root.

It is an accepted fact that people with disabilities constitute nearly 4-5% percent of our population and it is estimated that people with moderate to severe disabilities constitute 2-4 per cent. Having mentioned this, it is necessary to state that there is no authentic data on disabilities.

Therefore there is a need for a database, which can be used for planning purpose. This data is developed using the following statistics, formulae and rates:

1. India's 2001 census actual figures.
2. UN Statistics library data on age group classification of India's population based on 2001 census.
3. UNDP rate of disability calculations (Dr Helander, Prejudice and Dignity).

India added about 181 million persons between 1991-2001, which is more than the estimated population of Brazil, the fifth most populous country in the world. India's share of the world population is 16.7 percent. The percentage decadal growth of the country as a whole has declined from 23.86 during 1981-1991 to 21.34 during 1991-2001. Thus, India has registered a fall in its decadal growth rate by 2.52 percent points, which is the sharpest decline since independence. Among the major states Bihar has recorded the highest increase in the percentage decadal growth from 28.47 during 1981-91 to 28.43 during 1991-2001. During 1991-2001, the lowest growth rate was recorded in Kerala 9.42 percent followed by Tamil Nadu (11.19) and Andhra Pradesh (13.86). Andhra Pradesh has shown the sharpest decline among all the major states (10.34 percent). The average annual exponential growth rate has declined from 2.14 percent in 1981-91 to 1.93 percent during 1991-2001.

Uttar Pradesh continues to be the most populous state in the country with 16.17 percent of India's population followed by Maharashtra (9.42 percent) and Bihar (8.07 percent). In fact the population of Uttar Pradesh (166 million) is more than the estimated population of Pakistan. It would be interesting to note that almost two third of India's population lives in States and Union territories which show decline in growth rate during the decade 1991-2001 as compared to the previous decade.

India now has 57 more persons per sq.km. as compared to 1991. West Bengal is the most densely populated state in the country with 904 persons living per sq.km. followed by Bihar with 880.

**EDUCATION FOR ALL AND CHILDREN WITH DISABILITIES:  
INTERNATIONAL POLICY AND PRACTICE BY PHYLLIS MAGRAB,  
PHD, DIRECTOR, GEORGETOWN UNIVERSITY CENTER FOR CHILD  
AND HUMAN DEVELOPMENT**

Published in *Educating Children for Democracy*, Issue Number 6, Winter/Spring  
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**Issue Addressed**

The right to education is a basic human right and the foundation for a more just society. Half a century ago the Universal Declaration of Human Rights (1948) asserted education to be this basic human right, a right that was reaffirmed in the Convention on the Rights of the Child (1989). Importantly, the Convention also recognized that there are particular problems to overcome in order to truly ensure educational opportunities for all children. For this reason, the Convention has been followed up in recent years by a movement that has sought to turn the educational rights of the child into a reality. This movement, Education for All (EFA), was launched at the World Conference on Education for All in Jomtien, Thailand in 1990 by the major international and bilateral organizations and was attended by almost all of the nations of the world. In the year 2000, a decade later, 176 countries gathered in Dakar, Senegal at the World Forum on Education for All to review the progress made towards this goal. While, in general, countries have worked to address the educational rights of children and 10 million more children attend school each year, the tendency of countries to focus on the "easy to reach" and neglect those excluded from basic education for social, economic, or geographic reasons was notable in the review of progress. For example, 98% of children with disabilities in developing countries do **NOT** attend schools. As a result, the forum declared that Education for All must take into account the needs

of the poor and the disadvantaged, which includes, among others, those with special learning needs and assure that Education for All really means ALL.

### **IMPLEMENTATION OF THE WORLD PROGRAMME OF ACTION CONCERNING DISABLED PERSONS: TOWARDS A SOCIETY FOR ALL IN THE TWENTY-FIRST CENTURY**

General Assembly resolution 54/121 paragraph 10 urges Governments to cooperate with the Statistics Division of the Secretariat in the continued development of global statistics and indicators. The United Nations Statistics Division's work towards the improvement of disability statistics has focused on three objectives: (i) improvement of concepts and methods, (ii) technical cooperation to improve and promote national capabilities, and (iii) more effective compilation and dissemination of data.

A substantive accomplishment of the Statistics Division was the completion of the Guidelines and Principles for the Development of Disability Statistics. This publication is oriented to national statisticians to assist them in responding to the growing demand for data on disability. It addresses special issues raised by collecting and compiling statistics on persons with disabilities in national censuses and surveys, and in their analysis and dissemination for policy purposes.

The Statistics Division organized and hosted the International Seminar on the Measurement of Disability in collaboration with the United Nations Children's Fund (UNICEF), the Statistical Office of the European Communities (Eurostat), and the Centers for Disease Control and Prevention (CDC) of the United States of America.

The seminar brought together close to 100 participants from all regions of the world. Participants included experts in disability measurement from government

and research institutions, representatives of the disability community and policy makers.

The objectives of the meeting were: to review and assess the current status of methods used in population-based data collection activities to measure disability in national statistical systems, with particular attention to questionnaire design; to develop recommendations and priorities to advance work on the measurement of disability; and to contribute to building a network of institutions and experts, including producers and users of disability statistics to implement the developments in this field. A publication will be issued as a report of the meeting. Activities to follow-up on the measurement issues identified in the seminar for further research and development are being planned.

In relation to training and technical cooperation with countries, the Statistics Division participated in the Sub-regional Workshop on Disability Statistics for the eastern Asian region in April 2001. The following six countries participated: China, Hong Kong (China), Indonesia, Macao (China), Mongolia, Philippines, Republic of Korea, and Singapore. The objectives of the workshop were to address the training needs of national statisticians with responsibility for producing disability statistics, and of government personnel who require such statistics for policy formulation. Another aim of the Workshop was to bring together the producers and users of disability data in countries and in the sub-region for effective dialogue and partnership in the production and utilization of disability data.

## **INDIA: DISABILITY ADVOCATES WIN THE RIGHT TO BE COUNTED**

By National Centre for promotion of employment for disabled people  
(reprinted with permission)

India conducts census religiously every ten years. The official figure for the disabled population of india is 1.9% (source: nso survey 1991)! If we compare it with percentage of people with disabilities in other asian countries - china 5%, pakistan 4.9%, philipines 4.4%, nepal 5.0%, we can either pat our backs for literally having eradicated disability out of india or we can pinch ourselves in order to wake up and face the real truth.

1995 was an important year for the disability sector in india. It was the year when the disability act was passed. It was in that period that the disability sector also recognised one basic fact - that in the absence of correct statistics, people with disabilities will never get counted! It was promised to us by the then government that appropriate data will be collected in census 2001.

In the ninth five year plan (1997 - 2002), the planning commission also stated categorically that "to ensure planning for the welfare and development of the disabled more meaningfully, there is an impending need for the office of the registrar general and census commissioner, to revive their practice of 1981 census to collect the data on the size of the population of persons with various types of disabilities and to make it available through the next population census of 2001 AD."

### **PRESENTED AT ISEC 2000**

Self-empowerment for Women with Disabilities in Pakistan, Zahida Lari  
(PhD)

There are many human right issues in Pakistan, especially where women and disability are concerned.

Recent reports indicate that Pakistan's children face poor performance on social indicators, and that their health status continues to be deficient. Poverty keeps millions of working children out of school, and there is a high rate of childhood disabilities. The problems faced by girls are more severe, restricting their access to health care, education and recreation (UNICEF cited by the daily newspaper DAWN April 29 1993). Thompson (1998) reports that the dimensions of the problem facing the Government of Pakistan have not changed in recent years.

#### **The Way Forward: Where do we go from here?**

Thompson (1998) recommends that in the short term a working group should be established to develop a set of key indicators for the further development of special education in Pakistan. Improvements in the quality of support and provision for children with special educational needs can then be monitored within the framework of the Social Action Programme. It may be added that it is imperative that gender issues should be adequately addressed. According to the 1981 census (Government of Pakistan) female population comprises over 48 per cent of the total population and the educational and vocational needs of girls must be addressed.

The most recent Policy on Special Education was formulated by the Government of Pakistan in 1999. The National Policy for Special Education (1999) recognizes that the process of rehabilitation for many people with disabilities is an on-going one. It stresses also that public attitudes to the disabled need to be changed and the media can play an important role by portraying the disabled in a positive light and highlighting the successes of

persons with disabilities. Women must have an adequate representation in such programmes.

The National Policy (1999) also proposes certain fiscal concessions to be made for the disabled as well as providing them with legislative support. These should be implemented without delay and without prejudice to the female population.

It may be concluded that change is slow to take place, but some progress towards meeting the needs of the disabled population in Pakistan does seem to have occurred. Girls of today will be the mothers of tomorrow. It is encouraging to note that some steps, however small are being taken to promote their education.

## **NATIONAL COUNCIL ON DISABILITY: WASHINGTON, DC 2004**

### **Introduction**

Over the past few years, the National Council on Disability (NCD) has released several documents and reports related to the development of a UN Convention on the rights of people with disabilities. This briefing paper describes recent developments regarding the drafting of the convention document, and includes a discussion of the 3rd Session of the Ad Hoc Committee by a panel of consumers and experts.

### **Recent Developments**

In June 2003, the Ad Hoc Committee established a Working Group composed of representatives from 27 governments, 12 non-governmental organizations (NGOs) and one national human rights institution to prepare and present a draft treaty text that would be the basis for negotiations of a comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. The Working Group convened January 5 - 16, 2004 to prepare the draft text drawing from a wide variety of governmental and civil society contributions. During this drafting process the Working Group focused on the draft text of the Chairman of the Ad Hoc Committee (Luis Gallegos, Ecuador), the Bangkok draft text, and the Mexican draft text.

The text prepared did not represent the views of any specific delegation to the Working Group, but instead represented the work of the Group as a whole. It should also be noted that the method of work was unusual for a General Assembly body, in that NGO members enjoyed the same rights of participation as representatives of Member States. The draft included 25 proposed articles on topics concerning the promotion of positive attitudes to persons with disabilities statistics and data collection; equality and non-discrimination; right to life; equal

recognition before the law; liberty and security; freedom from cruel, inhuman or degrading treatment; freedom from violence and abuse; freedom of expression; respect for privacy; independent living; children with disabilities; education; participation in political and public life; accessibility; personal mobility; right to health and rehabilitation; right to work; social security; and participation in cultural life. The 25th article addressed monitoring, but did not include draft text relating to monitoring at the international level, and included only minimal text relevant to the creation of a national monitoring framework.

The draft prepared by the Working Group was used at the Third Ad Hoc Committee Meeting, which took place May 24 to June 4, 2004. A first reading of the proposed draft text during the meeting addressed Articles 1-24, international cooperation, and the preamble. In addition, discussions included a new article on women with disabilities, proposed during the meeting by the Republic of Korea. Consideration of the title, structure, sections of the preamble, definitions and monitoring were deferred until the 4th session of the Ad Hoc Meeting scheduled to take place from August 23 to September 4, 2004. Although there was agreement that the implementation of the convention would be a national responsibility, discussions also addressed additional implementation mechanisms such as international cooperation.

The discussions of the Ad Hoc Committee during the Third Meeting were held in open plenary, which facilitated the participation of accredited NGOs. Towards the end of the meeting the Committee considered the utility of proceeding on the last day with a second reading of the draft text and proposed amendments in "informals." These "informals" would be facilitated by different Member States, and would be "open" to enable the participation of NGOs. Despite strong support from a number of delegations, Member States could not reach agreement on whether NGOs should be permitted to participate in such meetings, and the final day was instead completed in formal plenary.

## **Panel Discussion**

NCD invited a panel of consumers and experts to participate in a discussion regarding the Third Ad Hoc Committee Meeting. The moderator for the discussion was Kathleen Martinez, NCD Board Member and NCD liaison to its International Watch Advisory Committee, who posed four questions to each panel member. Panel members included Sheikha Hissa, the Special Rapporteur on Disability at the United Nations; Charlotte McClain, South African Human Rights Commission; Celia Brown, National Association for Rights Protection and Advocacy; and Janet Lord, Landmine Survivors Network. The panelists' responses are provided below in their entirety.

**Kathleen Martinez: What were some of the main points of discussion in the Third Ad Hoc Committee Meeting?**

**Sheikha Hissa**

The purpose of the Third Ad Hoc Committee Meeting, which took place in New York from 23 May to 4 June, 2004, was to discuss the draft of the Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

In that respect, therefore, all the Articles of the Convention were discussed to a greater or larger extent. Some took far more time than anticipated, some were more contentious, and others went quite smoothly with almost unanimous agreement on all changes.

Whatever the case, the discussions were always rich and reflected the international community's commitment to the rights of people with disabilities and the serious efforts being made by all to come up with the best possible document.

All articles of the Convention were discussed at the Third Ad Hoc Meeting. However, it was agreed to defer the following articles to the Fourth Ad Hoc meeting, which will take place in August 2004: Article 1, Purpose; Article 2, General Principles; Article 3, Definitions; Article 4, General Obligations; and Article 25, Monitoring. Additionally, the need for an article to cover International Cooperation had almost unanimous support.

The major issues that generated a great deal of discussion and differing views were the following:

- The inclusion of a specific article dealing with women. It was generally the view of NGOs and most delegations of developing countries that an article on women is needed in the Convention in the same way that there is an article on children. The reason for that being that both groups require special attention, have special needs and need to be responded to in a specific way. It has also been documented, especially in developing countries and in more conservative societies and communities where women, who suffer discrimination, women with disabilities end up suffering double the discrimination, as well as exclusion and at times ostracism by their community. To date there has been no agreement on adding an article dealing specifically with women.
- Article 9 on equality before the law also generated energetic discussion particularly the segment dealing with the right of people with disability to manage and take full responsibility of their financial affairs and legal affairs.
- Article 6 on data collection and statistics brought out the point, particularly from developing countries, of the need to ensure that data and statistics on people with disabilities are not misused. The purpose of data collection and

statistics is to help decision/policy makers make informed decisions and set appropriate policies for the benefit of people with disabilities.

- Article 21 on the right to health and rehabilitation. It was agreed almost unanimously that this Article should be split into two; one dealing with Rehabilitation & Habilitation and the other with Health Care, with the clear understanding that rehabilitation is not strictly a medical issue. The trend towards rethinking rehabilitation as addressing all the needs of people with disabilities, as well as their families and communities should be clearly reflected in the Convention.
- Article 19 on accessibility reflected the wide gap between developing and industrialized countries about the understanding of accessibility. For many developing countries, accessibility means changing the physical environment and has not yet extended to all aspects of life.

### **Charlotte McClain**

Some of the main points were establishing separate articles on vulnerable groups within the disability sector. These include but are not limited to children and women. In terms of the substantive articles there was a lot of discussion on Article 23, Social security and adequate standard of living. Education was also a main point. Another point was the discussion on international cooperation. The issues of mobility, accessibility and universal design all received a considerable amount of time.

### **Celia Brown**

The main points of discussion are on individual self-determination and autonomy. Some member states have different opinions when it comes to forced intervention and forced institutionalization. The disability community has strongly stated that people

with disabilities have the right to make their own decisions and there should be a prohibition of forced interventions to correct or improve a perceived impairment.

### Janet Lord

The 3d session of the Ad Hoc Committee marked the first time that a convention text was put before the Ad Hoc Committee for a "first reading." The vast majority of the session was spent reviewing, article-by-article, a draft convention text consisting of a preamble and 25 articles drafted by the Working Group of the Ad Hoc Committee in January 2004. States as well as NGOs were afforded the opportunity to submit proposed modifications to the Working Group text on nearly every article, with the exception of the articles on definitions and monitoring which were deferred for future discussions.

Just a few highlights from this highly technical and detailed deliberation include:

- Debates around the degree of specificity to be provided by the articles in the convention (some States favor specificity of the type provided in the UN Standard Rules, others favor more generalized obligations and assert that greater specificity will jeopardize universal ratification).
- Whether and how to split the article on health and rehabilitation into two separate articles. The notion of splitting the article received support by many governments as well as NGOs.

How to address specific groups of people with disabilities within the convention: Should there be a separate article on children with disabilities (the Working Group did include a separate article)? Should there be a separate article on women with disabilities (as proposed by South Korea)? Should there be a separate article addressing groups at risk, such as people with disabilities in armed conflict or other emergency situations? Are some of these issues better addressed in an integrated manner throughout the convention?

Kathleen Martinez: What has been the role of disability oriented non-governmental organizations (NGOs) in the drafting process? To what extent are NGOs being utilized or excluded in drafting the convention?

**Sheikha Hissa**

NGOs played a great and important role which did not start with the Ad Hoc Committee discussions but from the very inception of the idea of a Convention. They were active contributors to the work of the Working Group and their influence was clear and felt in all the discussions. They were extremely visible and vocal throughout the process and enriched the document considerably. Many government delegations turned to their national or to the international NGOs for advice and interventions were sometimes drafted by NGO and government representatives together.

**Charlotte McClain**

The NGOs have been very instrumental in providing expert and experimental information on the needs and contextualizing the lives of people with disabilities. In the 3rd session at least 12 NGOs contributed from the floor. They have also been very successful in ensuring that cross disability issues are considered in the development of the Convention. Many of the NGOs are supporting government delegations. However, on the last day of the ad hoc meeting there was an intervention from the representative of the Africa group to review the participation of NGOs in the forthcoming session of the Committee; in my view this exclusion would be unfortunate.

In addition to the participation of NGOs it is also important to point out that National Human Rights Institutions have for the first time in the history of developing conventions been accorded recognition as national human rights institutions and contributed to the process of developing the Convention.

### **Celia Brown**

The disability oriented non-governmental organizations had a role in being a part of a working group made up of disability non-governmental organizations and member states drafting the convention. Their working group came together to draft a text of the convention in January 2004. The Chairman of the Ad Hoc Committee requested the participation of the disability non-governmental organizations and select member states to work together on a draft text of the convention for the Third Ad Hoc Committee meeting.

### **Janet Lord**

NGOs generally, and organizations concerned with the human rights of people with disabilities specifically, have played very active roles in the Ad Hoc Committee process to date. The majority of NGOs actively participating in the process are either disabled peoples' organizations or organizations with strong disability rights programming. At the outset of the process, NGOs lobbied hard to secure access to the process. Decisions taken by the Ad Hoc Committee during its first year of operation relating to NGO participation were generally favorable, though subject to the broad discretion of the Chair of the Ad Hoc Committee. In practice, the Chair (Ambassador Gallegos from Ecuador) has given great latitude to NGOs in facilitating their participation (e.g., he has been very generous in not imposing strict time limits on NGO oral interventions, always ensures that NGOs have the chance to speak in plenary on every issue, has been very open in meeting regularly with NGOs).

Subsequent meetings of the Ad Hoc Committee and its Working Group have continued to build on NGO participation in the process. NGOs continue, in increasing numbers, to serve as delegates on Member State delegations to the Ad Hoc Committee, thereby achieving the highest level of access, including

participation in closed or informal sessions where non-delegation NGO representatives are excluded. In addition, those NGOs who are not represented on government delegations continue to wield influence in various ways, giving oral interventions on the floor of the Ad Hoc Committee, organizing briefings on various issues for governmental and other participants, issuing written statements and position papers, and "working the corridors" to influence government positions. The high watermark of NGO participation in the process thus far was the representation of 12 NGOs on the Working Group (along with 27 governments and 1 national human rights institution) during the January 2004 session. No differentiation was made at all between governments and NGOs during the course of the Working Group. Some countries, however, continue to press for a reversion to more closed, informal sessions where NGOs would not be allowed to participate, even as observers without the right to speak. While a number of states favor continued participation at high levels (Mexico, EU, Canada, New Zealand), the opposition among a few (some African countries, some Asian countries) can serve to block consensus and therefore may still result in a roll back of NGO participation. For that reason, NGOs are closely monitoring the situation and preparing lobbying strategies.

### **National policy for persons with disabilities, 2002**

The need to make special provision of the members of the community who suffer from the effects of disabilities has long been recognized in Pakistan. Creation of Pakistan facilities for the education, training and rehabilitation of disabled persons is regarded as being of central importance concerning the rights of a significant percentage of our population.

Recent years have witnessed emergence of International movements for the empowerment of persons with disabilities through a number of international

conventions and agreements, which make Government of Pakistan a partner in the global movement for the betterment of this segment of society.

The provision of a comprehensive range of facilities for persons with disabilities from pre-natal care through education, vocational training, employment and support during adult life cannot be a matter for a single government department or agency. The provision and growth of services of real quality will require the active cooperation of a large number of relevant organizations at federal, provincial, local and NGO level, along with involvement of family, professionals and communities at large.

The policy is formulated with a background of information about the number of disabled children and adults in Pakistan based upon the WHO estimates of 10% of the population and upon more detailed information provided by Pakistan – based studies including the National Census, 1998. The National Census Report of 1998 however indicates a low estimate of 2.49% of the total population, based on the reported cases of persons with disabilities. Grouping of the 2.49% figure into age specific groups indicates the following estimated maximum level of need:

- i) Children under five who require some form of support, as well their families 10.34%
- ii) Children aged 5-14 who require some form of special education. 23.09%
- iii) Young people upto the age of 29 who will need further education, training and employment opportunities. 23.98%
- iv) Disabled Adults requiring other welfare support and assistance. 25.15%.

- v) The disabled senior citizens requiring more special facilities.  
16.56%.

The distribution of different disabilities within the defined population of disabled persons, as indicated by the 1998 census, provides a useful guide for planning programmes as under: -

i)	Physically Handicapped	19%
ii)	Mentally Handicapped & Insane	14%
iii)	Multiple disability	8.21%
iv)	Visually Impaired	8.6%
v)	Hearing Impaired	7.40%
vi)	Others	43.33%

(Not classified but included as disability)

The above figures include those who have mild or temporary conditions but who will require access to some form of support or assistance. Studies undertaken in Pakistan and elsewhere, however, indicate that a smaller group of individuals exists which have serious or severe disabling conditions, which are in need of detailed intervention and support on a long term basis. The size of this group will amount to 2% of the population of the disabled persons, according to estimates.

### **Vision:**

The overall vision of the National Policy for Persons with Disabilities in keeping with our Islamic way of life, is to provide by 2025 environment that would allow full realization of the potential of persons with disabilities through their inclusive

mainstreaming and providing them full support of the government, private sector and civil society.

### **Goals:**

Empowerment of persons with disabilities, irrespective of caste, creed, religion, gender or other consideration for the realization of their full potential in all spheres of life, specially social, economic, personal and political.

### **Mission statement**

Optimal development of persons with disabilities for the realization of their full potential in all walks of life, specially in the areas of health, education, social, economic and vocational needs, for the fulfillment of their present as well as future requirements.

### **Guiding principles:**

- The Constitutional guarantees and accession to international instruments on human rights, as the reiteration of the Islamic principals of justice and equality.
- Non-discrimination and gender equity at all levels.
- Holistic approach in the overall interest of persons with disabilities covering all aspects of their lives in the community.
- The rights based approach rather than welfare concepts in program planning and implementation.
- Active collaboration from all stakeholders, government, private sector and civil society.

## **Aims and objectives:**

To persons with disabilities:

2. Provide access to facilities which may lead to their integration and mainstreaming in all spheres of life.
3. Ensure they are involved in planning and implementing educational, training and rehabilitation programs for themselves, their families and communities;
4. ensure that they are able to enjoy their rights and opportunities as other citizens do;
5. ensure that they have equal opportunities and access to medical, education, social, psychological, vocational training, employment and rehabilitation, without any discriminations;
6. ensure that the legislation relating to employment and rehabilitation of persons with disabilities is adequately formulated and is strictly enforced;
7. expand service infrastructure which is adequate to accommodate and cover all persons with disabilities both in urban and rural areas;
8. harness modern technology, tools and skills to streamline national policy, planning, programming and service delivery for effective redressed of disabilities;
9. remove financial and technical constraints posing hindrance in the way of proper implementation of programmes.

## **Strategies:**

- Develop and launch advocacy campaigns to address special groups, such as policy makers, opinion leaders, youth and adolescents.
- Increase ownership of disability issues by the stakeholders and strengthen their participation in the process of service delivery and program design.

- Adopt a shift from exclusive system of education to that to inclusive education for the children with disabilities.
- Ensure the provision of quality services to all segments of age groups for persons with disabilities, through expansion and strengthening of service delivery infrastructure.
- Expand, coordinate and monitor a comprehensive network of services for person with Disabilities in Pakistan.
- Build strong partnerships with concerned Line Ministries, Provincial Line Departments and the Private Sector (NGOs), by providing assistance / guidance through advocacy, training, monitoring and other means of participation and quality assurance.
- Decentralize program management and services delivery to provincial and district level.
- Ensure training and education of parents and communities to recognize special needs of persons with disabilities.

### **Services And Aftercare Of The Down Syndrome**

The child with Down syndrome is in need of the same kind of medical care as any other child. The pediatrician or family physician should provide general health maintenance, immunization, medical emergencies, and offer support and provide counseling facilities to the family. There are, however, situations when children with Down syndrome need special attention.

1. Sixty to eighty percent of children with Down syndrome have hearing deficits. Therefore, audiologic assessments at an early age and follow up hearing tests are indicated. If there is a significant hearing loss, the child should be seen by an ear, nose and throat specialist.
2. Forty to forty five percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo

cardiac surgery and often will need long term care by a pediatric cardiologist.

3. Intestinal abnormalities also occur at a higher frequency in children with Down syndrome. For example, a blockage of the food pipe (esophagus), small bowel (duodenum), and at the anus are not uncommon in infants with Down syndrome. These may need to be surgically corrected at once in order to have a normal functioning intestinal tract.
4. Children with Down syndrome often have more eye problems than other children who do not have this chromosome disorder. For example, 3 percent of infants with Down syndrome have cataracts. They need to be removed surgically. Other eye problems such as cross-eye (strabismus), near-sightedness, far-sightedness and other eye conditions are frequently observed in children with Down syndrome.
5. Another concern relates to nutritional aspects. Some children with down syndrome, in particular those with severe heart disease often fail to thrive in infancy. On the other hand, obesity is often noted during adolescence and early adulthood. Providing appropriate nutritional counseling and anticipatory guidance can prevent these conditions.
6. Thyroid dysfunctions are more common in children with Down syndrome than in normal children. Between 15 and 20 percent of children with Down syndrome have hypothyroidism. It is important to identify individuals with Down syndrome who have thyroid disorders since hypothyroidism may compromise normal central nervous system functioning.
7. Skeletal problems have also been noted at a higher frequency in children with Down syndrome, including kneecap subluxation (incomplete or partial dislocation), hip dislocation, and atlantoaxial instability. The latter condition occurs when first two neck bones are not well aligned because of

the presence of loose ligament. Approximately 15 percent of people with Down syndrome have atlantoaxial instability. Most of these individuals, however, do not have any symptoms, and only 1-2 percent of individuals with Down syndrome has a serious neck problem that requires surgical intervention.

8. Other important medical aspects in Down syndrome, including immunology concerns, leukemia, Alzheimer disease, seizure disorders sleep apnea and skin disorders, may require the attention of specialists in their respective fields.

### **Education Services And Vocational Opportunities For Children With Down Syndrome**

Today early intervention programs, pre – school nurseries, and integrated special education strategies have demonstrated that youngsters with Down syndrome can participate in many learning experiences which can positively influence their overall functioning.

Children with Down syndrome, like all children, can benefit from sensory stimulation, specific exercises involving gross and fine motor activities, and instruction in cognitive development. Also, preschool nurseries play an important role in the young child's life since exploring the environment beyond the home enables the child to participate in a broader world.

Later, the school can give the child a foundation for life through the development of academic skills and physical as well as social abilities. Experiences provided in school assist the child in obtaining a feeling of self-respect and enjoyment. School should provide an opportunity for the child to engage in sharing relationships with others and help to prepare the child to become a productive citizen. Contrary to some views, all children can learn, and they will benefit from placement in a normalized setting with support as needed.

During adolescence, youngsters with Down syndrome should be exposed to prevocational training in order to learn good work habits and to engage in proper relationships with coworkers. Appropriate vocational counseling and job training will result in meaningful employment, and this, in turn, should lead to a feeling of self-worth and of making a contribution to society.

### **Learning Processes**

New & diversified programs & services for the retarded have created a need for new techniques & procedures in training & behavior management since the early 1960s, various researchers have demonstrated the usefulness of learning theory in filling this need. Careful psychological testing is often required to discover the child's actual learning potential. During learning process, some times learning handicap occur, for this strict behavioral management is recommended.

### **Toilet Training**

Many parents of retarded children prefer to change diapers rather than go through a prolonged disciplinary process with uncertain results. Strict methods, of behavior modification have proved successful in training even profoundly retarded adults. The child should be dressed in simple clothes and training pants, and should be provided with a comfortable toilet seat that remains in the bathroom.

### **Eating Habits**

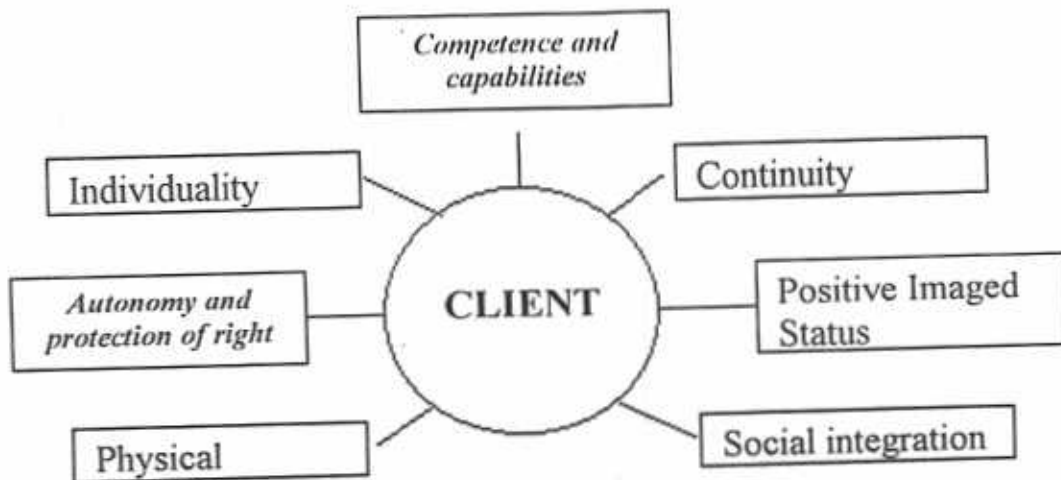
Excessive weight gain is life, threatening in prader – Willi syndrome, in which the weight of short adults exceed 140 kg (308 lbs).

Weight gain is a hopeful sign to parents, motivating them to continue feeding until the child is obese. Lack of exercise is a common cause of obesity among retarded children and adults.

An obesity prevention program includes dietary control, exercise, and family counseling. A pediatrician, nutritionist, mental health counselor and family coordinator may coordinate with all team members for successful programme.<sup>6</sup>

### Role Of The Remedial Therapist

Remedial therapy for the client with a mental handicap will aim for improvement in:



### Physiotherapy

The role of the physiotherapist is to optimize the functional potential of individual who have a mental handicap by facilitating alteration of their motor and sensory performance using physician agencies.

Physiotherapists assess and analyze the movement and resolving the physical problems of clients suffering neuromuscular, muscular skeletal and cardiovascular respiratory system, symptoms of disease or disability and assisting in the prevention of problems related to these e.g. physical deformity. The physiotherapist analyses the client's physical problems takes account of the

<sup>6</sup> Dr. Puschel, Director, Child Development Center, Rhode Island Hospital, Providence, Rhode Island was awarded The Arc's 1990 Distinguished Research Award.

client's current psychological, cultural and social influences and is based on an analysis of movement and function and the desire to promote good health.

Physiotherapy intervention consists of:

**Treatment of acute clinical conditions:**

- Respiratory problems
- Orthopedic injuries
- Skin conditions

**Motor and Sensory Stimulation:**

- Individually by mobilizing, positioning and exercise for movement, strength, balance and coordination.
- Remedial recreation therapy e.g. hydrotherapy, rebound therapy and riding.
- Relaxation.

**Speech Therapy**

The speech therapists assess, diagnosis and give treatment in relation to communication and feeding difficulties. Speech therapy includes formal tests and observations and will result in a diagnosis relating to problems of:

**Pre – Language Skills**

- Language:* the understanding and use of words
- Sound system:* the range of sounds used in the composition of words.
- Articulation:* the use of lips, tongue and facial muscles in speaking.
- Fluency:* the flow of speech
- Voice:* the presence or absence of voice and its quality

### **Rebound Therapy**

This involves the trampoline as an item of therapeutic equipment for the development of movement, coordination, balance and relaxation with people, with a mental handicap. The use of the equipment, which has beneficial, physical and psychological effects, improves motor skills body awareness, concentration general health and confidence.

### **Hydrotherapy**

Hydrotherapy literally means treatment – using water. The benefits of hydrotherapy are to improve mobility, balance, coordination, blood circulation and breathing. The warm water widens the clients experiences of movements and encourages confidence leading to increased function and independence.

### **Art, Drama, And Music Therapy**

Arts, drama and music play an important role in the facilitation of learning the development of movement and the use of imagination Art, drama and music are fun and their use encourages, communication, role play, mobility, imagination, relaxation and group interaction in an informal therapeutic settings.

### **Horse Riding**

Horse riding under close supervision, usually on a one to one basis, can produce the most dramatic changes in a persons with a mental handicap. The client frequently experience great achievement when able to ride on a horse.

### **Conductive Education**

Conductive education is a combination of therapy and education conducted with groups of clients simultaneously to provide opportunities to learn how to function through movement on a 24 – hour basis. Conductive education was developed in Hungary where disabled clients with a reasonable intellectual ability are selected,

therapist usually works with those mentally retarded people who often use a modified form of conductive education.

### **Passive Movements And Patterning**

To learn any new physical skill passive demonstration and frequent repetition are necessary. Passive movement of the limb or body may have to be repeated frequently for the best result.

Some people with severe mental retardation need passive movements to be undertaken to reduce physical deformity caused by abnormal muscle tone leading to tight muscles and joint contractors.

### **Adaptability**

The remedial therapist tries to change the environment of the client. He makes the learning process interesting, updating fun and memorable, new experiences and daily activities. The remedial therapist always remember that every one responds differently.

### **Advisory**

The advisory role is an important function of the remedial therapist in the interdisciplinary team approach. The remedial therapist is often the person approached for advice regarding the provision of appropriate equipment required to facilitate the independence of the client and or the career.

### **Chiropody**

The chiropodist is a specialist in the assessment, diagnosis and treatment of foot problems. The majority of people face the problems of the toes and feet. The chiropodist has a major role in the prevention of sever deformity and consequent poor gait, and early intervention is essential. Careers, clients, and other team members are taught to identify early signs of foot problems so that swift treatment can prevent further trouble. Chiropodist always contact with physiotherapist

because if the retarded children get any surgical footwear problem, he can discuss it with him.

### **Working Together**

Team work and group work is very important. The team members must communicate, share ideas, skills and responsibilities, and cross professional boundaries. Every team member will describe the aims and objectives of their intervention to all other team members. Special attention should be paid to the client. There should be close collaboration between the teams responsible for pediatric and adult services.

### **Relaxation Techniques And Positioning**

The caretaker of sever mentally handicap with sever physical disability after seeking advice how to position their clients may achieve their maximum functional potential. Accurate placing of pillows and cushions, of the table in relation to the chair and the feet in relation to the floor or supporting surface are almost important. Relaxation technique both local to a limb and general for the whole body can be most advantageous socially and personally.

### **Interdisciplinary Approach**

Because children with mental retardation often have other problems, it is necessary to involve a team of practitioners from different areas (e.g., child psychiatrist, social worker, child psychologist, special education teacher, speech and language specialist, and community agencies), in the comprehensive diagnosis. This type of interdisciplinary team approach is relatively new but is considered to be imperative for comprehensive assessment, treatment, and management of children with mental retardation (Lubetsky, Mueller, Madden, Walker, & Len, 1995). A natural extension of the interdisciplinary approach is the involvement of the family in the decision-making process. In fact, recent government and educational initiatives such as Public Law 99-457 and Public Law

102-119 *require* the involvement of parents and professionals in early intervention services (Lubetsky et al, 1995). A family-centered interdisciplinary approach begins with an assessment of the child (including school history, obtained from parents and school records), family (family marital and parenting history), and community resources. Medical, developmental and psychiatric histories are obtained. Behavioral analysis, psychoeducational, speech and language testing are completed. Medical and neurological assessments are performed. The team presents these results to the parents who are actively involved in evaluating and implementing treatment recommendations (Lubetsky, et al, 1995).

## **Intervention**

### **Psycho-educational Intervention**

As a result of federal legislation developed with the aid and encouragement of a number of advocacy groups (i.e., the Individuals with Disabilities Education Act; Public Law 94-142, Public Law 99-457, and Public Law 102-119), children and adolescents with mental retardation or related developmental disorders are entitled to free and appropriate intervention. Appropriate intervention should be based on the needs of the child as determined by a team of professionals, address the priorities and concerns of the family, and be provided in the least restrictive most inclusive setting (i.e., where they have every opportunity to benefit from interacting with nondisabled peers and the community resources available to all other children).

### **Infant/Toddler Services**

Services to infants and toddlers can be home-based, center-based, or some combination of the two. The nature of the services should be determined based on the results of the child assessment and family priorities for the child. These should be used to develop an Individual Family Service Plan for the child which includes all parties participating in the intervention and is coordinated by a Services

Coordinator (case manager) who is available and acceptable to the family. The services may include assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, nursing intervention, nutrition counseling, occupational therapy, physical therapy, case management, and transportation to services.

### **Preschool and School Services**

Services to preschool children, ages 3 through 5, and school-aged children, 6 through 21, can be home-based, but are more frequently center-based. As in the case of infants and toddlers, a team evaluation and parent input is used to develop an intervention plan. This plan, the Individualized Education Plan (IEP), details the objectives for improving the child's skills and may include family or parent-focused activities. Services may include special education provided by a certified teacher and focused on the needs of the child, child counseling, occupational therapy, physical therapy, language therapy, recreational activities, school health services, transportation services, and parent training or counseling. These services should be provided in the most inclusive least restrictive setting (e.g., a regular preschool program, Headstart Center, child's home).

### **Social/Interpersonal Intervention**

Social and interpersonal interventions can be both preventative and therapeutic. As noted above, children with mental retardation are at an increased risk for behavioral disorders. Therefore, a variety of group social and recreational activities should be included in the child's educational program. These activities should include non-disabled peers and may include participation at birthday parties, attending recreational activities such as ball games and movies, participating in youth sports activities, and visiting community sites such as the

zoo. The goal of these activities should be to teach appropriate social skills relevant to group participation and building self-esteem.

Parents also may benefit from prevention activities. Respite care provided by trained individuals can afford parents the opportunity to address their own needs (e.g., personal time, medical appointments, socializing with peers, etc.). They can be much more effective in parenting when their own needs have been met. Social or parent support groups can also be an outlet for parents to discuss their feelings with individuals who have similar experiences. These groups may be syndrome specific (e.g., Parent Advocates for Down Syndrome) or more generic in nature.

Therapeutic interventions with the children and families may include family therapy, individual child behavior therapy, parent training, and group therapy with mildly mentally disabled children and adolescents focusing on developing appropriate social skills. Child behavioral interventions can be used to teach self-care, vocational, leisure, interpersonal, and survival skills (e.g., finding a public restroom). Disruptive behaviors such as tantrumming, self-injury, noncompliance, and aggression toward others can also be addressed through behavioral techniques. The most frequent form of behavioral intervention for problematic behavior involves differential reinforcement of incompatible and/or other behaviors (Batshaw & Perret, 1992).

### **Psychopharmacological Intervention**

Treatment specifying the use of medication should only be considered when a particular psychiatric condition known to benefit from a particular drug coexists with the mental retardation or developmental disability. This may take the form of a severe depression, obsessive-compulsive disorder, attention deficit-hyperactivity disorder, or a variety of other psychiatric disorders. There are few well controlled studies of drug treatments with children who have mental retardation. It should also be noted that the use of medication as a form of chemical restraint should be

avoided. In addition, when drug treatment is used, it should only be one component of an overall treatment approach (Batshaw & Perret, 1992).

### **Level of Family Involvement**

How and when should families be included in decision making? There is no standard formula for answering this question. Families, like individuals, vary tremendously. Nevertheless, there are some issues that must be considered when involving families in team decisions about their child with a disability. First, the team must be receptive to including families in the decision-making process. This involves some effort on the part of the non-family team members to encourage family participation. In addition, the team must decide what child and family concerns are related to enhancing the development of the child. These should be the focus of generating family-oriented service delivery alternatives.

Second, the team must consider the level of knowledge and understanding of the family related to the disability of the child and/or the service/treatment options. If families are to participate in the decision-making process they must have the knowledge necessary to select appropriate alternatives. It is unfair to assume that families will not understand or cannot make appropriate decisions about the care of their child. They are the consumers and need to be given the chance to make an informed choice.

Finally, once the family has an adequate understanding of the condition and service/treatment alternatives, they may need to be nurtured through the team decision-making process. Most families have never been faced with participating as a member of a team of professionals and may initially be reticent or non-participatory in discussions unless they are specifically invited to do so. Certainly as a primary care provider the parent or family member has more at stake than the other team members. Over time, however, the cautious or reticent family member may become an active and vital team member.

## **Encouraging Parent Participation**

Health and education professionals who participate as team members must actively pursue parent-professional partnerships in the decision-making process. The logical first step is to acknowledge the value of the parent-professional relationship. Parents should be viewed as equal partners who can make important and necessary contributions in the planning, decision-making, process. If professionals are reluctant to or refuse to acknowledge parents as partners in the process, they run the risk of alienating them resulting in a lack of interest or participation in necessary services. Once the non-family team members accept the parents or other relevant family members as equal partners in the planning process, strategies to encourage continued active participation should be developed and implemented.

## Summary

Mental retardation characterized by significantly subaverage intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developing period. It also can vary in degree or level. Major levels of Retardation are:

- a) Mild deficiency
- b) Moderate deficiency
- c) Sever deficiency

Psychiatric services to Mentally retarded children are provided differently by their extent and nature of retardation. First of all Psychiatrist take the families history then child's case history after at current family situation, structure and social functioning of the child and his family. After it treatment plan many people are involved e.g. family, teachers, different types of therapists careers, Social Workers, Doctors, Day care Officers, Dietician, Psychiatrists and Chiropodist. Action plan is formed jointly. During the treatment the team workers keep in their mind that every individual is different from each other by their, I. Q level Physique and emotional characteristics. Residential services can also be used by professionals.

Improved Preventive measures before conception, during pregnancy and at delivery are necessary. Society has many stereotyped attitudes and prejudices about mental retardation and they affect the parents being member of society often, for this they need counseling about their child.

Many retarded children will be able to learn and read reasonably well and do simple computational work. Retarded children in motor & sensory behaviors, art and crafts, attention, persistence in working at a task and avoidance of being distracted, and of distracting of other. Rehabilitation programs made for those

retarded children which able to do something. Govt. of Pakistan is a started 125 centres for retarded children. Govt. of Pakistan raised the quota in employment's for mentally retarded people from 1% to 2%. In Pakistan 10% people are mentally retarded. Preventive measures are needed for this, the media can play positive role.

*CHAPTER - 3*

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*RESEARCH METHODOLOGY*

## **Chapter – 3**

### **Research Methodology**

#### **Universe of the study**

The universe of this study includes three special education schools. Two of them are situated in Peshawar and one in Quetta.

#### **Respondents of the study**

The study is based on the information obtained from: -

##### **a) Parents of retarded children**

The parents of retarded children were interviewed to find out the genetical causes of retardation and the environmental factors effecting child development and retardation, to find out endogamy as a social factor to retardation, and the attitude perception of others towards retarded member of their families.

##### **b) Neighborhood of retarded children**

Families from neighborhood of the mentally retarded children were interviewed, to find out the society's viewpoint about the retarded children and their attitudes towards the particular families having the retarded children.

#### **Sample Size**

As mentioned earlier that information will be collected from two different kinds of respondents. Therefore, hundred respondents will be selected from each of the two categories of respondents.

#### **Sample Technique**

Simple Random sample technique was used for the selection of the respondents.

## **Tools For Data Collection**

Interview schedule was used as a tool for data collection. For this purpose, two different interview schedules were constructed for both categories of the respondents.

## **Data analysis**

The statistical analysis of the data is done keeping in view the objectives of the study.

## **Time schedule**

1. Comprehensive study of the retarded children and the causes of retardation (two months).
2. Collection and study of relevant literature related to this field available to the research (two months).
3. Interviewing 100 mothers of the retarded children (three months).
4. Data analysis & information of results (two months).
5. Report writing & putting in the computer disc (six months).

## **Pre-testing**

Ten mothers and ten neighbors were pre-tested from each province. Duplication of the questions was corrected and few more questions were added.

**CHAPTER - 4**

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***TABULATION/DATA ANALYSIS***

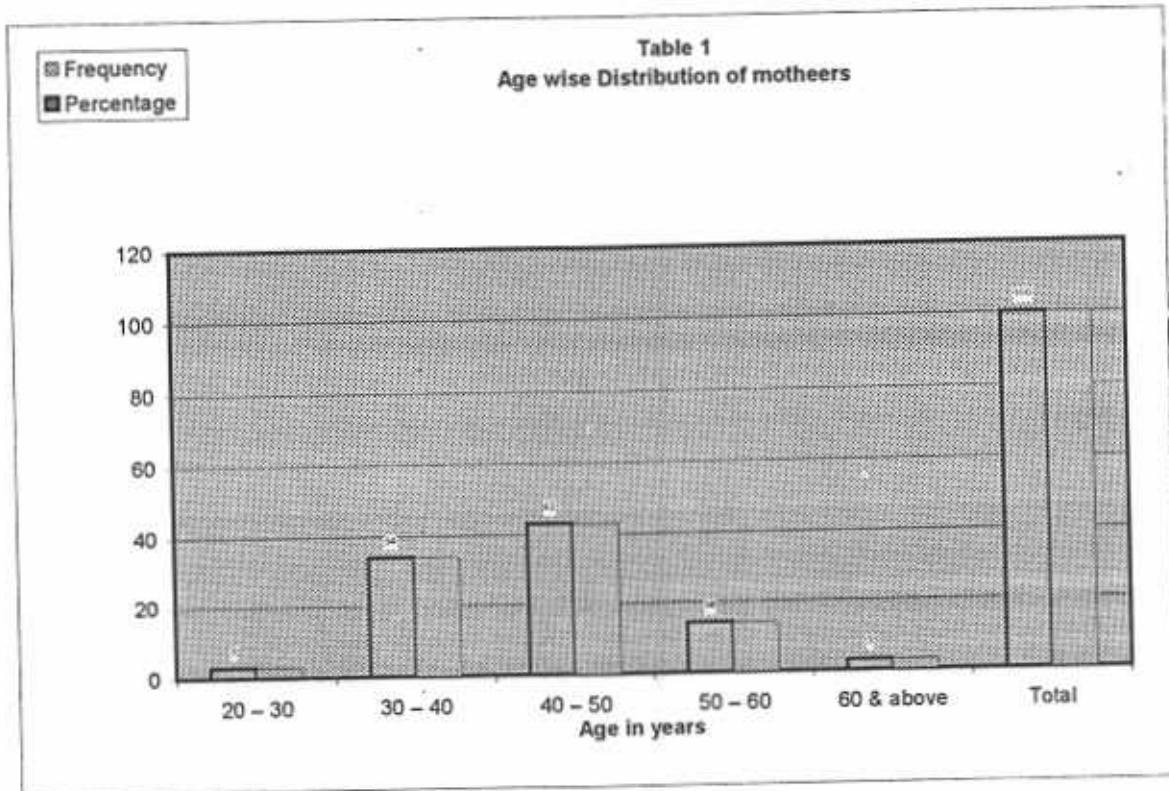
## Chapter – 4

### Tabulation And Data Analysis

#### Section – I Information of The Mothers

**Table – 1: Age Wise Distribution Of The Mothers of the Mentally Retarded children**

Age in years	Frequency	Percentage
20 – 30	3	3%
30 – 40	34	34%
40 – 50	43	43%
50 – 60	14	14%
60 & above	3	3%
Total	100	100%



**Table No. 1** shows that the age factor of the parents play vital role in mental retardation during marriage and conception of the fetus. It is believed that parents have age above than 40 have more chances of disabilities among the children especially mental retardation.

In this study the age of the mothers having mentally retarded children ranged from 20 to 60 years, the majority of the respondents being 43% were between 40 – 50 years of age, while 34% were between 30 – 40 years of age. Those who were above 50 years of age were 14%, while 3% were above 60 years. This is also showing the trend of marriage or desire of children during this age very low means in very few cases parents goes for children during this age that is why there is few number of disabilities during the age of 50 or 60.

The data shows that majority of mothers of the mentally retarded children were between the age of 40 – 50.

**Table – 2: Educational Status Of The Mothers**

Educational status	Frequency	Percentage
Illiterate	72	72%
Primary	6	6%
Middle	2	2%
Matric	8	8%
Intermediate	7	7%
Graduation	3	3%
Post-graduate	1	1%
Professional	1	1%
Total	100	100%

**Table 2**  
Educational status of the mothers

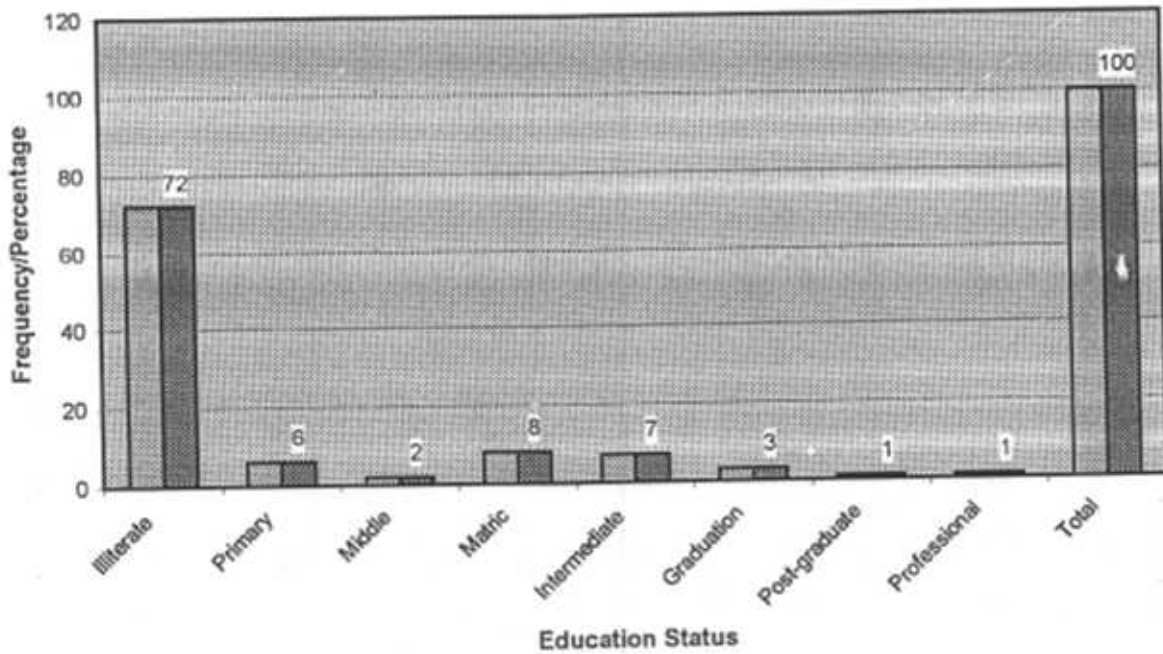


Table 2. Shows the educational status of the respondents.

Illiteracy is the root cause of so many health problems. Due to illiteracy the people go for early marriage and cousin marriages, which is one of the cause of the problems. Illiteracy is the multi-dimensional phenomena regarding mental retardation. As it clear in the finding that majority 72 % of the respondents were illiterate.

72/100 i.e. 72% were illiterate, 6/100 (6%) took primary education, 2/100 (2%) were educated upto middle, 8/100 (8%) were upto Matric, 7/100 (7%) were upto Intermediate, 3/100 (3%) were graduates, 1/100 (1 %) was post graduate and 1/100 (1 %) respondent took Professional Education.

Over all educational situation shows the high rate of illiteracy and only one respondent was post-graduate and one took the professional education.

Majority of the mothers of the mentally retarded children were illiterate.

**TABLE – 3: Occupational Status Of The Mothers**

Occupation	Frequency	Percentage
House wife	88	88%
Teacher	8	8%
Doctor	1	1%
Industry worker	3	3%
Total	100	100%

Frequency  
 Percentage

Table 3  
Occupational status of the mothers

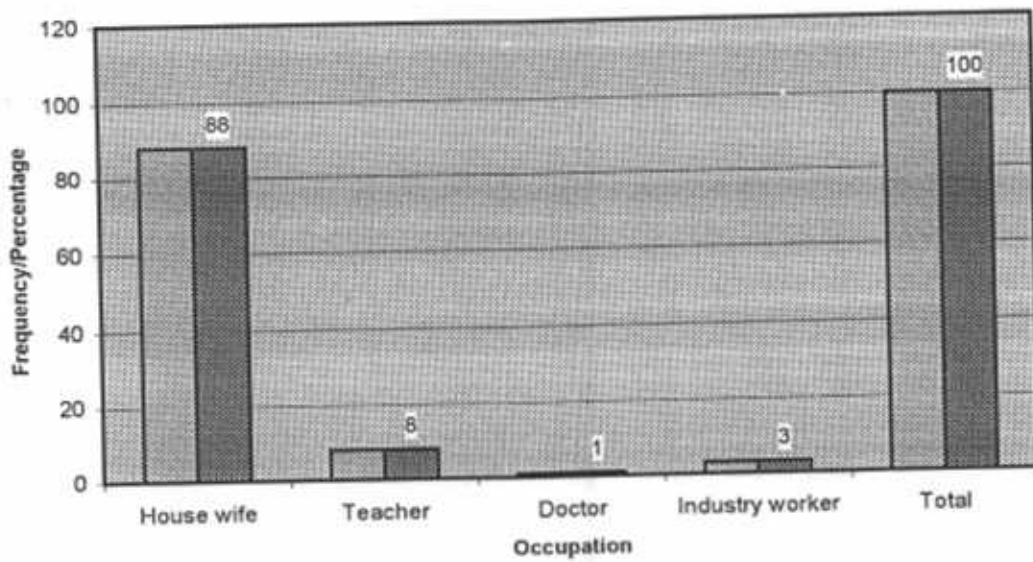


Table -3 shows the occupational status of the respondents.

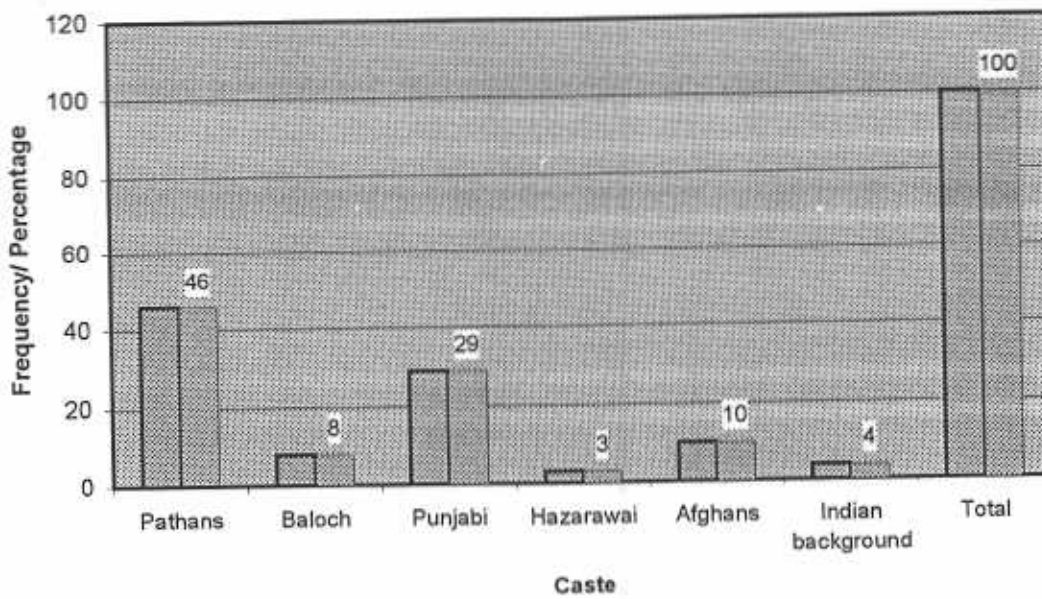
Pakistani society has a patriarchal based family system. There is a very clear-cut demarcation of role and status between the two genders. Man controls the external activities of the household while women is responsible for the internal management of the household. Due to which the status of the female restricted to only few roles i.e. rearing and bearing of children, cooking and washing etc. As it is clear in this study that 88/100 (88%) respondents were housewives, only 8/100 (8%) were teachers, 1/100 (1%) respondent was doctor and 3/100 (3%) were working as Labourer in industries. Therefore:

**Table – 4: Caste Wise Distribution Of The Mothers**

Caste	Frequency	Percentage
Pathans	46	46%
Baloch	8	8%
Punjabi	29	29%
Hazarawai	3	3%
Afghans	10	10%
Indian background	4	4%
Total	100	100%

**Table 4**  
Caste wise edistribution of the mothers

■ Frequency  
■ Percentage



**The table 4 indicates the caste of the respondents.**

The social system of a society plays vital role in social functioning of the people. Every society has stratification people in different classes, groups and caste, which shows their traditional trend. The more rigid stratification the more would be conservatism and stickiness with their norms and values. As Patan is the most important and major segment of our society and especially in NWFP. They have a very clear-cut customs and tradition base on caste system. Cousin marriages and much number of children is very common among them. This system has crucial role in prevalence of disabilities. As it is indicated in this study that majority of the respondents 46/100 (46%) were Pathan and 8/100 (8%), Punjabi 29/100 (29%), Hazarawai 3/100 (3%), Afghan comprise 10/100 (100%) and Indian who are permanently residing here were 4/100 (4%)

**Table – 5: Socio-Economic Status Of The Mothers**

Socio-economic status	Frequency	Percentage
Upper	10	10%
Middle	50	50%
Lower	40	40%
Total	100	100%

Frequency  
 Percentage

**Table 5 Socio-economic status of the mothers**

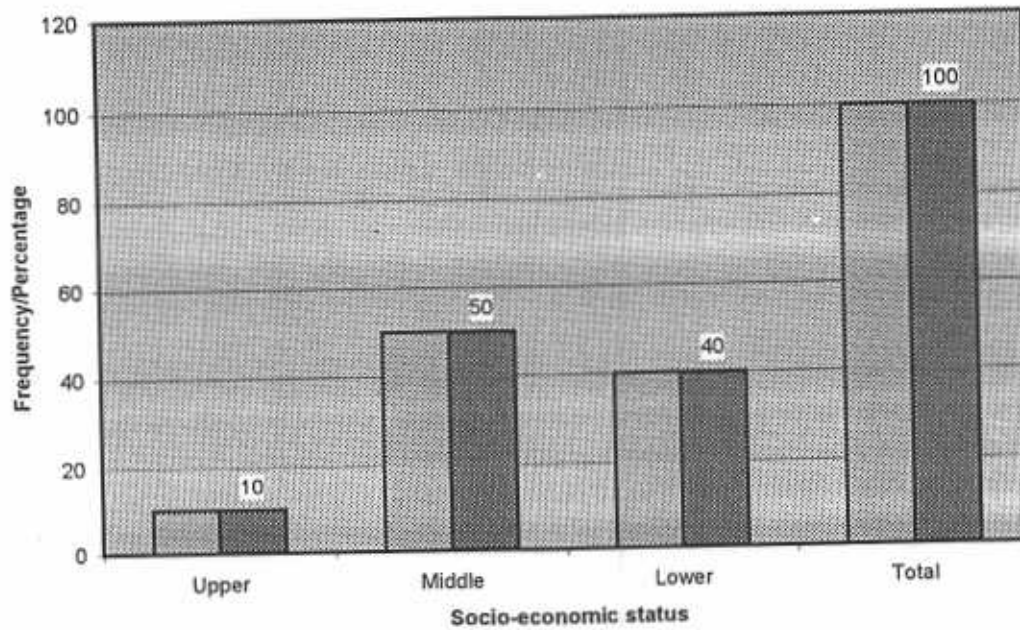


Table 5 shows the socio-economic status of the mothers. It is difficult to explain

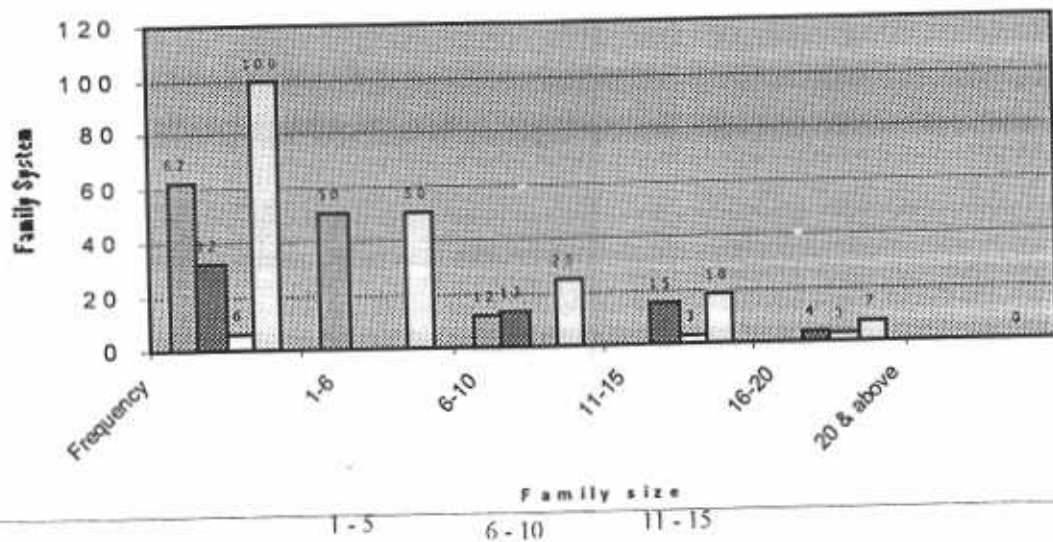
As it is already mentioned that socio-economic condition of people plays vital role in normal or abnormal health. The people belongs to upper families can feed their children properly and can take proper balance diet during pregnancy. In this study 10/100 (10%) respondents were from upper families. 50/100 (50%) were from middle socio-economic background while the remaining 40/100 (40%) from the lower socio-economic background.

**Table – 6: Family Structure Of The Respondent**

Family system	Frequency	Family size				
		1-5	6-10	11-15	16-20	20 & above
Nuclear	62	50	12	-	-	-
%	62%	50%	12%	-	-	-
Joint	32	-	13	15	4	-
%	32%	-	13%	15%	4%	-
Extended	6	-	-	3	3	-
%	6%	-	-	3%	3%	-
Total	100	50	25	18	7	0
%	100%	50%	25%	18%	7%	-

- Nuclear
- Joint
- Extended
- Total

**Table 6**  
**Family structure of the respondent**

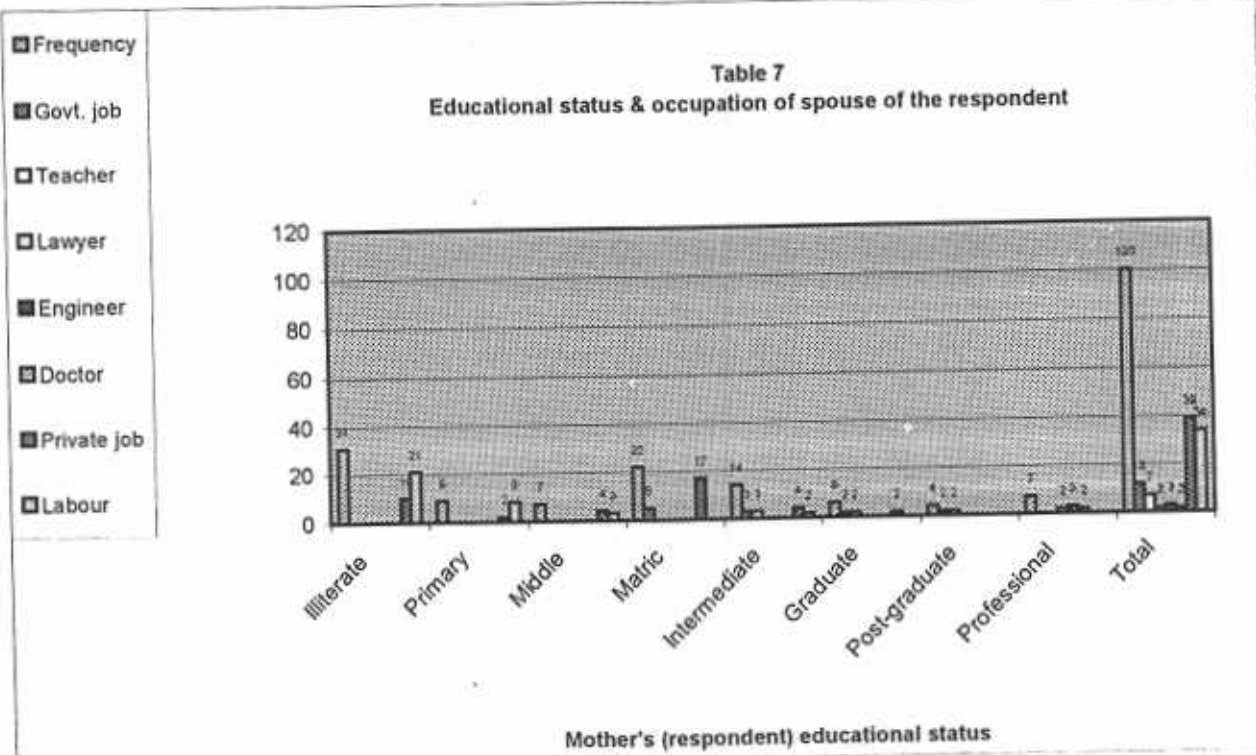


The table 6 Shows the family structure and family size of the respondents, 62% families were living as nuclear families out of 62%, family size of 50% respondents was between 1-5 members while the family size of the remaining 12% respondents was in between 6-10. Regarding family system 35% respondents were living in joint families, out of 35% respondents the family size of 15% respondents was between 11-15 members of 13% respondents was between 6-10, and 4% respondents was in between 16-20 members, 6% respondents were living in extended families. 3% (3/100) respondents' family size was between 11-15 members while family size of 3% respondents was between 16-20.

The family system of majority of the respondents was nuclear and their family size was in between 1-10, only 6% respondents were living in extended family system and their family size was in between 11-20.

**Table – 7: Educational Status And Occupation Of Spouse Of The Respondent**

Mother's (Respondent) Educational status	Frequency	Occupation of the spouses						
		Govt. job	Teacher	Lawyer	Engineer	Doctor	Private job	Labour
Illiterate	31	-	-	-	-	-	10	21
%	31%	-	-	-	-	-	10%	21%
Primary	9	-	-	-	-	-	2	8
%	9%	-	-	-	-	-	2%	8%
Middle	7	-	-	-	-	-	4	3
%	7%	-	-	-	-	-	4%	3%
Matric	22	5	-	-	-	-	17	-
%	22%	5%	-	-	-	-	17%	-
Intermediate	14	3	3	-	-	-	4	2
%	14%	3%	3%	-	-	-	4%	2%
Graduate	6	2	2	-	-	-	2	-
%	6%	2%	2%	-	-	-	2%	-
Post-graduate	4	2	2	-	-	-	-	-
%	4%	2%	2%	-	-	-	-	-
Professional	7	-	-	2	3	2	-	-
%	7%	-	-	2%	3%	2%	-	-
Total	100	12	7	2	3	2	39	34
%	100%	12%	7%	2%	3%	2%	39%	34%



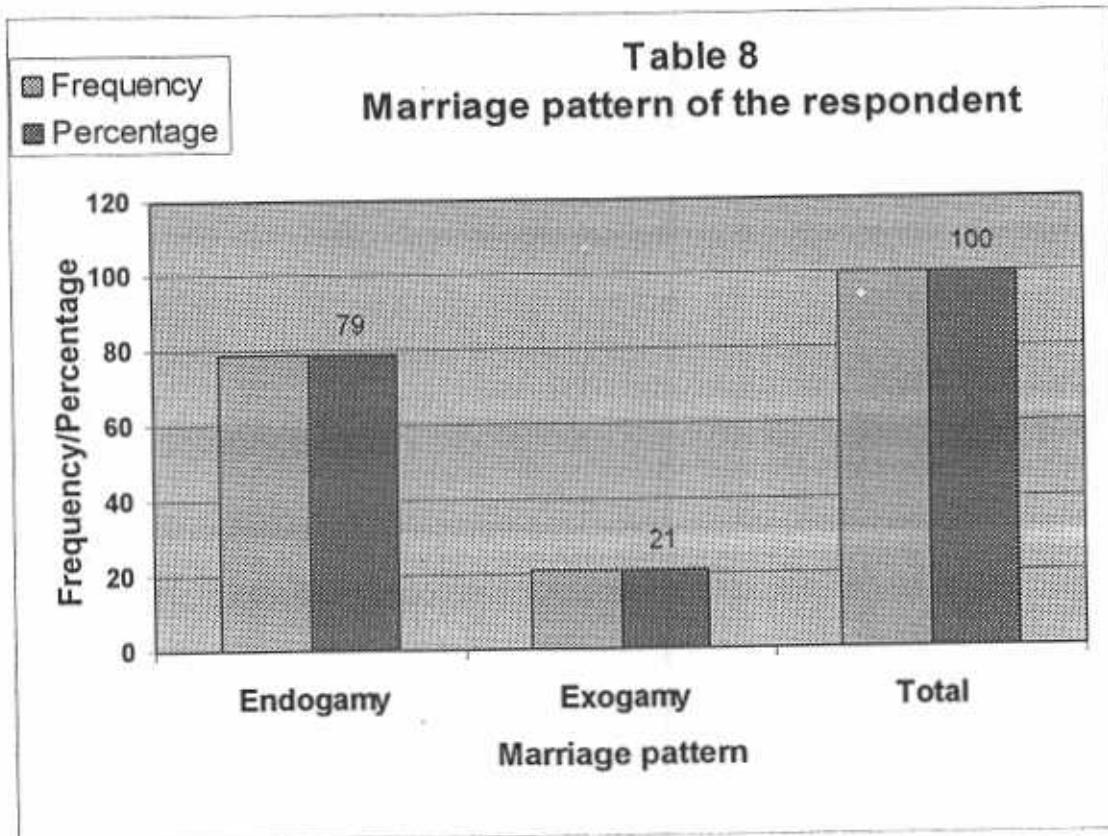
The above table indicates the educational status and occupation of the respondents spouse. The number of illiterate respondents was 31 out of them 10 were doing private jobs and 21 were working as labour. The respondents who took education at primary level they were 9 and out of 9, two were doing private job and 8 were working as labour, 7 respondents took education at middle level out of them, 4 were doing private jobs and 3 were working as labour. 22 respondents education level was Matric, out of them, 5 were doing govt. jobs and 17 were doing private jobs. 14 respondents education level was Intermediate out of them 3 respondents were doing Govt. jobs, 3 were teachers, 4 were doing private jobs, 2 were working as labour and 2 were in Army. Graduates were only 6, 2 were doing govt. jobs, 2 were working as teachers and 2 were doing private jobs. 4 respondents were postgraduate, out of 4, two were doing govt. jobs and 2 were working

as teachers. Seven took professional education 2 were lawyers, 3 were Engineers and 2 were Doctors. Educational level of the respondents was very poor

Majority of the respondents were illiterate and working as labour and private jobs, only 7% were professionally educated and working as professionals.

**Table – 8: Marriage Pattern Of The Respondent**

Marriage pattern	Frequency	Percentage
Endogamy	79	79%
Exogamy	21	21%
Total	100	100%



The table no. 8 shows the marriage pattern of the respondents.

Marriage patterns played very important and crucial role in the causes of disabilities. It is scientifically proved that families where the tend of marriages within the families high have more chances of disabilities due the weak zygotes. As Pakistani joint family system where the people give preference to internal marriages. Therefore in this study it clear that majority of the respondents have disabilities were 79/100 (79%) which justify that assumption that endogamy is a root cause of mental retardation.

Similarly only 21/100 (21%) respondents having disabilities.

**Table – 9: Age At The Time Of Marriage And Birth Of The Child**

Respondents age	Frequency	Mother's age at the time of retarded child's birth					
		15-20	21-25	26-30	31-35	36-40	Above 40
15 – 20 years	66	18	38	10	-	-	-
%	66%	18%	38%	10%	-	-	-
21 – 25 years	29	-	21	6	2	-	-
%	29%	-	21%	6%	2%	-	-
26 – 30 years	4	-	-	2	2	-	-
%	4%	-	-	2%	2%	-	-
31 – 35 years	1	-	-	-	-	-	1
%	1%	-	-	-	-	-	1%
36 – 40 years	0	-	-	-	-	-	-
%	-	-	-	-	-	-	-
Total	100	18	59	18	4	-	1
%	100%	18%	59%	18%	4%	-	1%

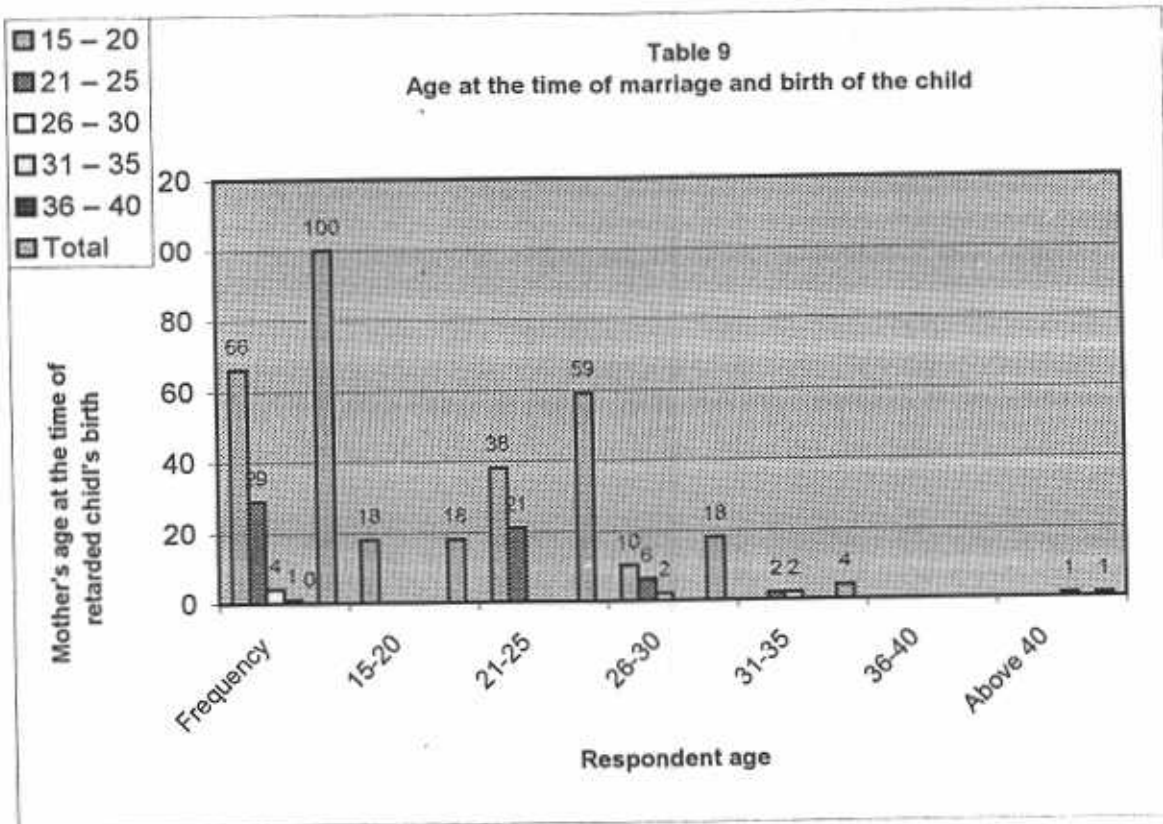
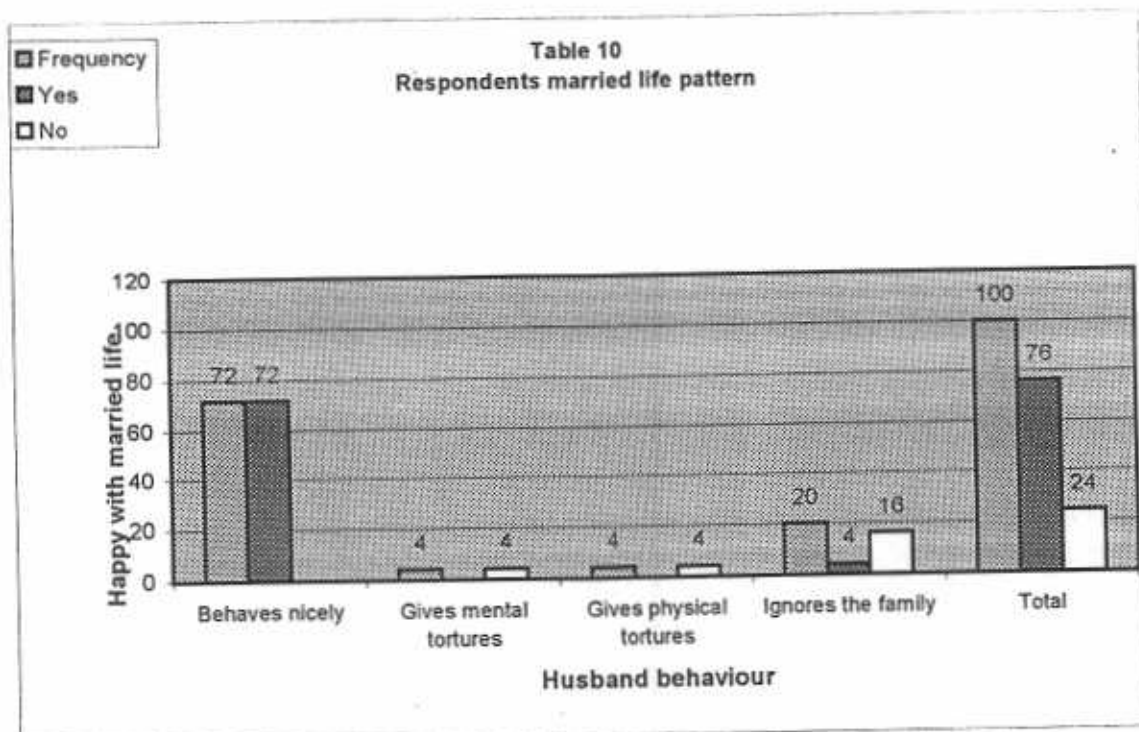


Table 9 shows the respondents age at the time of her marriage and at the time her retarded child's birth, 66% respondents age at the time of marriage was between 15 – 20 years, out of 66% mothers 18% age at the child's birth was 15 – 20 years. 38% respondents age was between 20 – 25 years at their marriage time out of them 21% mother's age was between 20 – 25, at the time of their retarded child's birth, 6% respondents age was 25 – 30 years, and only 2% mother's age was between 30 – 35 years, 4% mothers age at the time of their marriage was 25 – 30 years, at the birth of their retarded child, 2% mothers age was 25 – 30 years, 1% mother's age was 30 – 35 years and 1% mothers age was above 40 years at the time child's birth.

Therefore, majority of the mothers age at the time of their marriage was between 15-20, and their age at the child's birth was in between 15-30 only 1% was marriage at the age of 30-35 and at the child's birth her age was in between 30-35.s

**Table – 10: Respondents Life Pattern**

Husband behaviour	Frequency	Happy with life	
		Yes	No
Behaves nicely	72	72	-
%	72%	72%	-
Gives mental tortures	4	-	4
%	4%	-	4%
Gives physical tortures	4	-	4
%	4%	-	4%
Ignores the family	20	4	16
%	20%	4%	16%
Total	100	76	24
%	100%	76%	24%



The table-10 shows the respondents married life pattern and husbands behaviour. Out of 100 respondents spouses 72% behave nicely with them during pregnancy 20% family members ignored the respondent during pregnancy they did not take care of her , 4% gives mental tortures and 4 spouses gives physical tortures to the respondents. 72% respondents were happy with their married life and 24% respondents were not happy with their married life.

Over all behavior of the respondents spouse was nice and only 8% gives mental and physical tortures to the respondents.

Therefore, majority of the respondents spouse behaves nicely and they were happy with their married life only 4% respondents spouse give them mental and physical tortures and they were not happy with their married life.

**Table – 11: Disease During Pregnancy**

Disease	Frequency	Medication	
		Yes	No
Thyroid operation	1	1	-
%	1%	1%	-
Jaundice	1	1	-
%	1%	1%	-
High fever	3	3	-
%	3%	3%	-
Bleeding	1	1	-
%	1%	1%	-
<b>Total</b>	<b>6</b>	<b>16</b>	<b>84</b>
<b>%</b>	<b>6%</b>	<b>16%</b>	<b>84%</b>

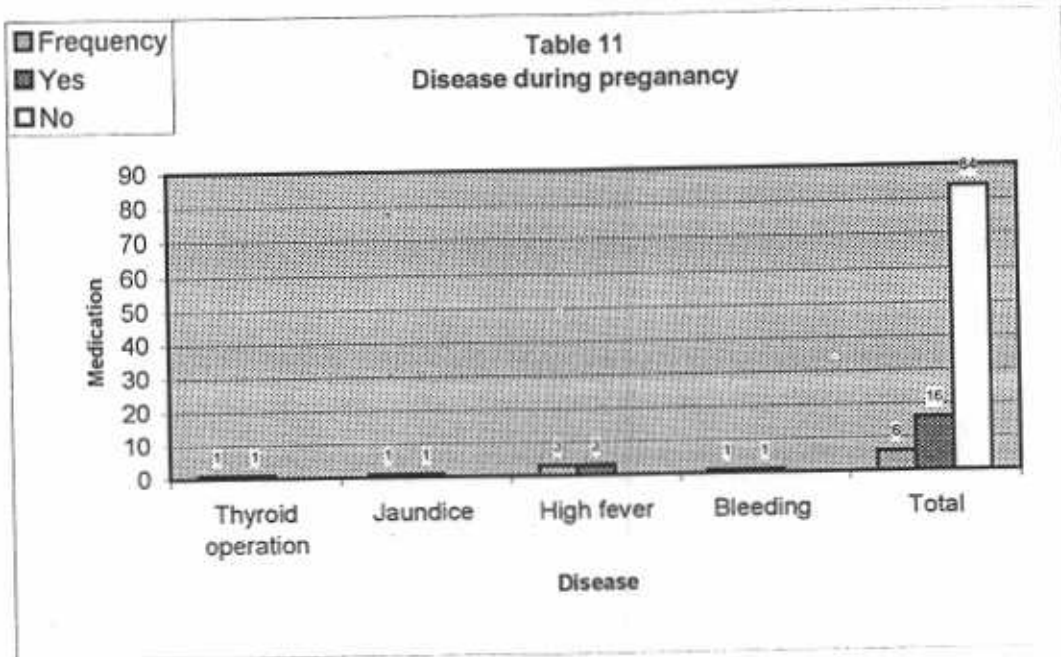


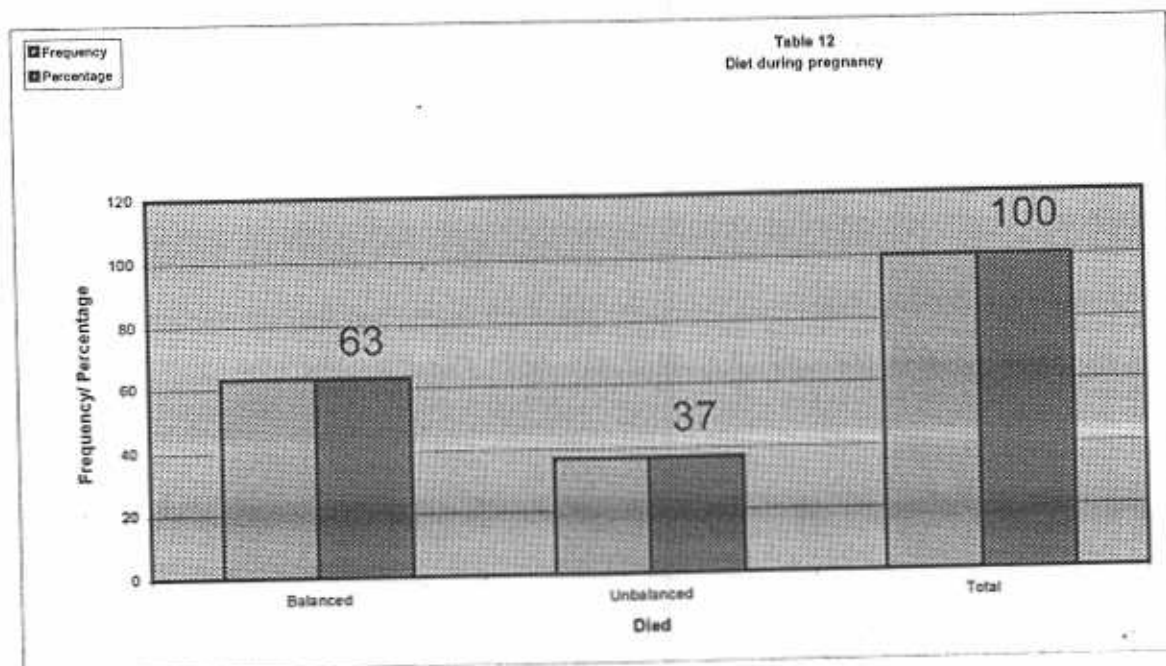
Table – 11

explains the respondents diseases during pregnancy. Six respondents got different diseases and 16 respondents told that they took different medicines during pregnancy the medication can also the cause of mental retardation. One respondent got Jaundice and she took medicines during her disease, one respondent's Thyroid operation was done and she took medicines for it, 3 got high fever and took antibiotics and one respondent told that bleeding was started during pregnancy and she took medicines for it. Other 10 respondents did not tell the reasons why they took medicines.

Majority of the respondents got high fever and other got jaundice, thyroid operation and spotting during pregnancy.

**Table – 12: Diet During Pregnancy**

Diet	Frequency	Percentage
Balanced	63	63%
Unbalanced	37	37%
Total	100	100%



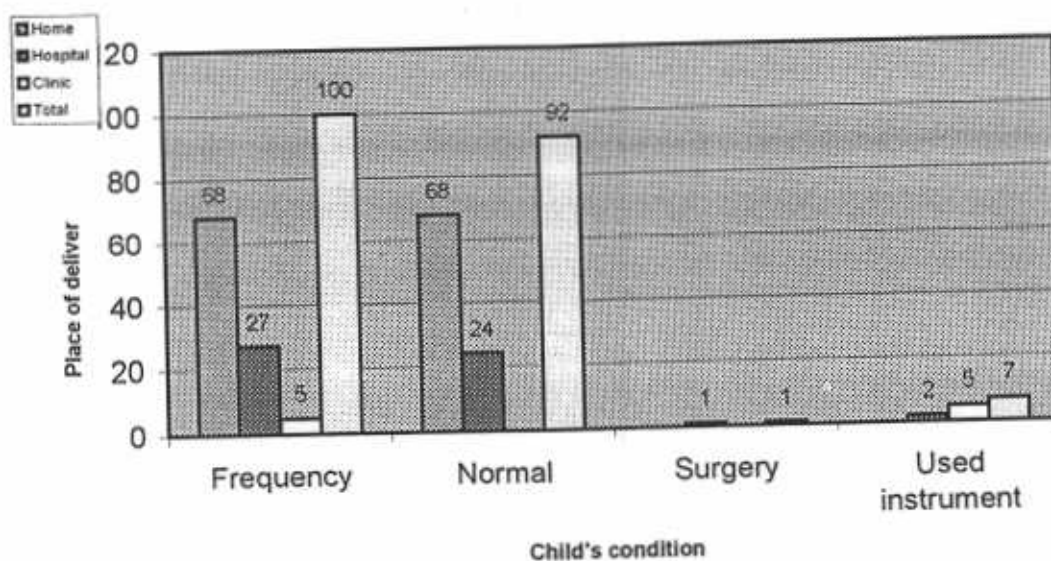
### Explanation:

Table – 12 explains the diet of the respondents during pregnancy, 63/100(63%) respondents took balanced diet during pregnancy. When researcher asked about balance diet the respondents were well known about it, only 37/100(37%) respondents did not take balanced diet because of their poor economic condition but they were also well known of balanced diet. The table proves the assumption that poor economic condition affects the physical and mental growth of fetus. Majority 63% of the mothers took balanced diet during pregnancy and 37% did not.

**Table – 13: Delivery Of Child**

Place of delivery	Frequency	Child's Condition		
		Normal	Surgery	Used instrument
Home	68	68	-	-
%	68%	68%	-	-
Hospital	27	24	1	2
%	27%	24%	1%	2%
Clinic	5	-	-	5
%	5%	-	-	5%
Total	100	92	1	7
%	100%	92%	1%	7%

**Table 13  
Delivery of child**



The table – 13 indicates the places of delivery of the retarded children. Out of one hundred retarded children 68/100(68%) were delivered normally at home, 27/100(27%) were delivered in hospital, one was delivered by surgery and for 2/100(2%) instruments were used, 5/100(5%) were delivered at clinic and instruments were used for delivery.

Frequency shows that the number of normal deliveries at home was higher as compared to less number of deliveries at clinic with instruments only one child was delivered by surgery.

Most of the people prefer deliveries at home. The untrained dies and unavailability of staff can be the cause of mental retardation in children.

**Table – 14: Family Relation During Pregnancy**

Family relations	Frequency	Respondent accepted the pregnancy	
		Happily	Not happily
Good	48	48	-
%	48%	48%	-
Bad	8	-	8
%	8%	-	8%
Satisfactory	44	37	6
%	44%	37%	6%
Total	100	85	15
%	100%	85%	15%

Table no. 14 explain's the respondents relation with her family during pregnancy, 48% respondents relations with their family members were good and they accepted pregnancy happily but 8/100(8%) respondents faced bad attitudes of the family they did not accept pregnancy happily, 44/100(44%) respondents relations were satisfactory, out of them 6% did not accept pregnancy happily.

**Table – 15: Attitude Of The Respondent During Pregnancy**

Feelings of the respondents	Frequency	Choice for pregnancy	
		Wanted to keep	Wanted to abort
Happy	42	41	1
%	42%	41%	1%
Worried	11	10	1
%	11%	10%	1%
Depressed	46	44	2
%	46%	44%	2%
Total	100	95	5
%	100%	95%	5%

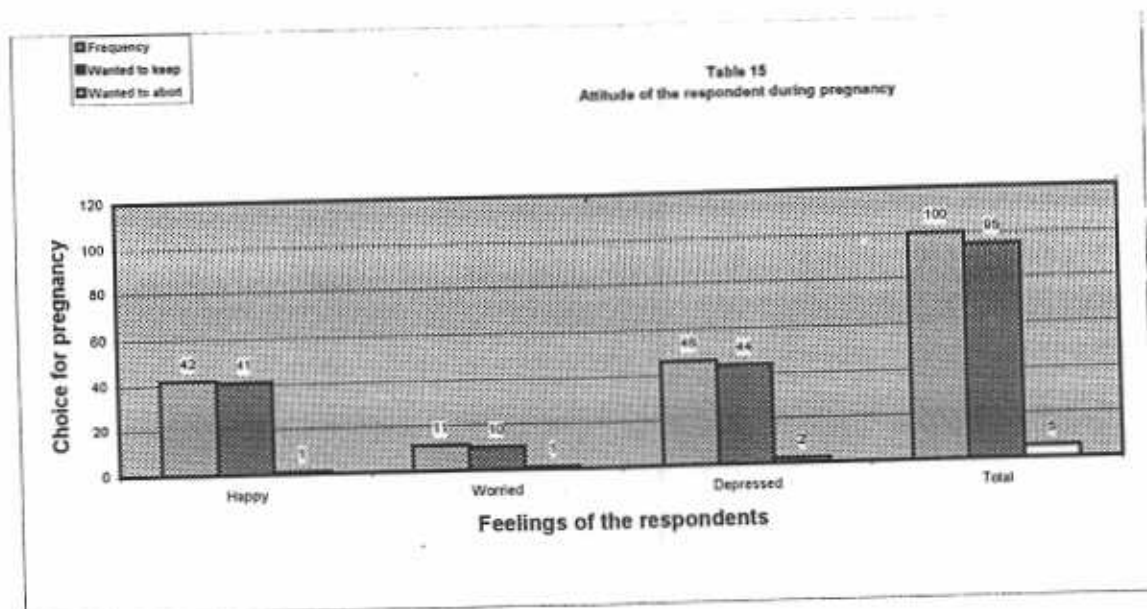


Table – 15 shows the feelings of the respondents during pregnancy. Out of one hundred respondents 42/100(42%) were happy, 11/100(11%) were worried because few of them had retarded child in the family and few were facing domestic problems 46/100(46%) were depressed during pregnancy because the mother had retarded child, 95/100(95%) respondents want to keep the child and 5/100(5%) respondents were not willing to give birth to the child and tried to abort the baby because the mother's had fear to gave birth to another retarded child. 41/100(41%) respondents were happy, 10/100(10%) were worried and 44 were depressed but they wanted to keep the child.

**Table – 16: Gender And Age Profile Of The Child**

Gender	Freq.	Age		
		5 – 10	10 – 15	15 & Above
Male	77	45	21	11
%	77%	45%	21%	11%
Female	23	10	9	4
%	23%	10%	9%	4%
Total	100	55	30	15
%	100%	55%	30%	15%

**Table 16**  
Gender and age profile of the child

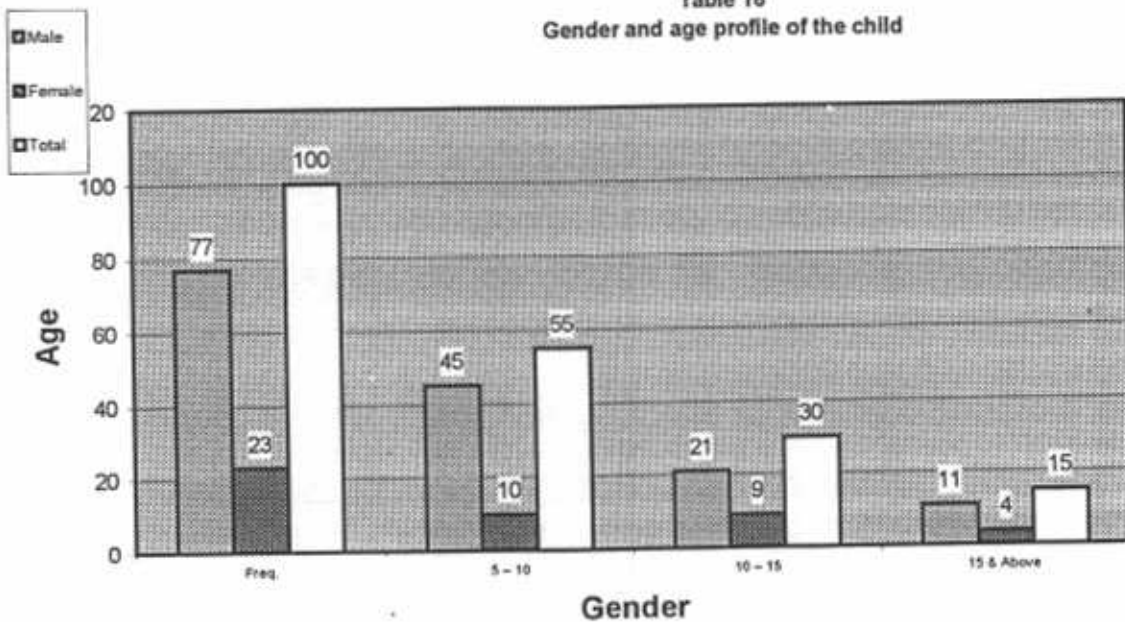


Table 16 explain's the Gender and age profile of the children 77/100(77%)children were male, and belong's to5-10 year's age group 12/100 (21%) were in 10-15 age group, and 11/100( 11%) children were above 15 years. 23/100(23%) children were female,10/100( 10%) children were 5 – 10 year's age group,9/100( 9%) children were belong to 10-15 years age group, and 4/100(4%)children were above 15 years.

The number of male mentally retarded children shows the gender biaseness.In few families during interviewing mother's researcher found mentally retarded females at home,researcher asked to parents why you did not send retarded girls to special education schools,the parents replied we don't want to give them education.there real place is home.the girls should learn domestic work at home

**Table – 17: Types Of Mental Retardation Found In Children**

Type	Frequency	Percentage
Down's syndrome	17	17%
Cerebral Palsy	12	12%
Slow learner	25	25%
Multiple mental retardation	25	25%
Sever/complete mental retardation	21	21%
Other	0	0%
Total	100	100%

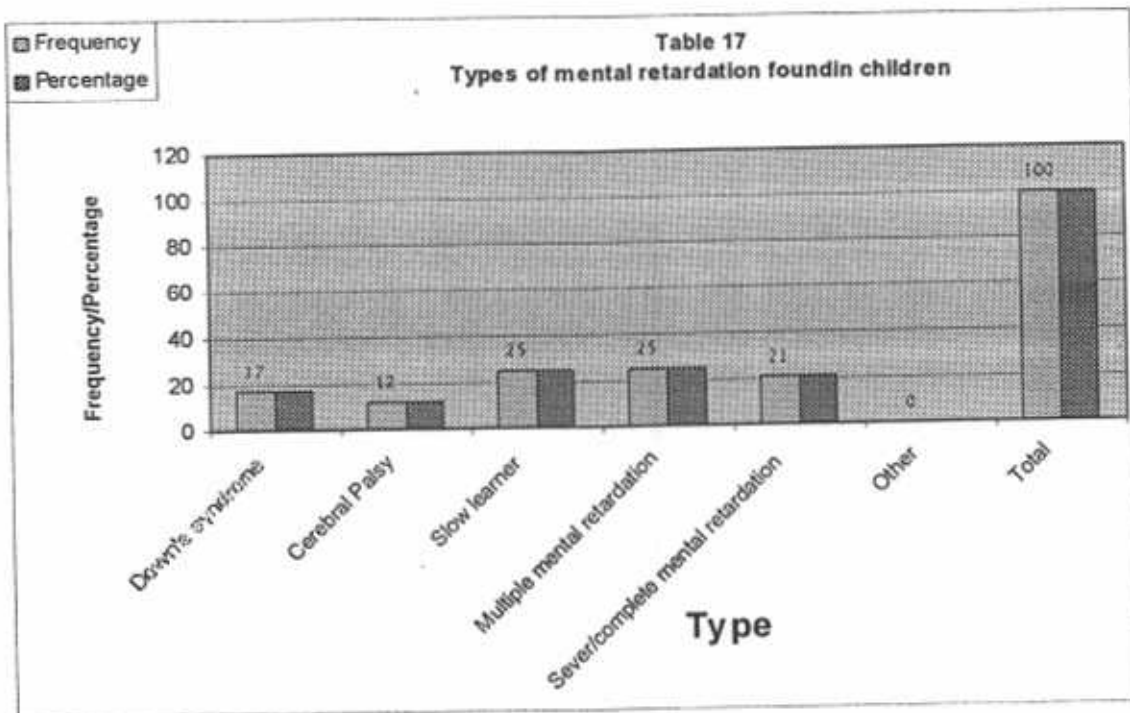


Table 17 explains the types of mental retardation found in children. 25/100(25%) children were slow learner's, they did not pick the things quickly. 25/100(25%) mentally retarded children got different multiple diseases like deafness, speech and vision problem. all problems affect their daily life. They did not understand the things correctly. These disabilities were affected at their parents' also. 12/100(12%) children had cerebral palsy. 25/100(25%) children were facing multiple mental retardation . 21/100(21%) children were severely mentally retarded. They were not able to do things for themselves. They just come to the institute and sit whole day there was no improvement seen in their mental and physical abilities. The parents and teachers were hopeless but they were trying their best for the children.

**Table – 18: Change In Child’s Overall Development**

Change	Freq.	Type of change				
		Social	Intellectua l	Mental growth	Physical	No change
Yes	90	30	27	11	22	10
%	90%	90%	27%	11%	22%	10%
No	10	-	-	-	-	-
%	10%	-	-	-	-	-
Total	100	30	27	11	22	10
%	100%	30%	27%	11%	22%	10%

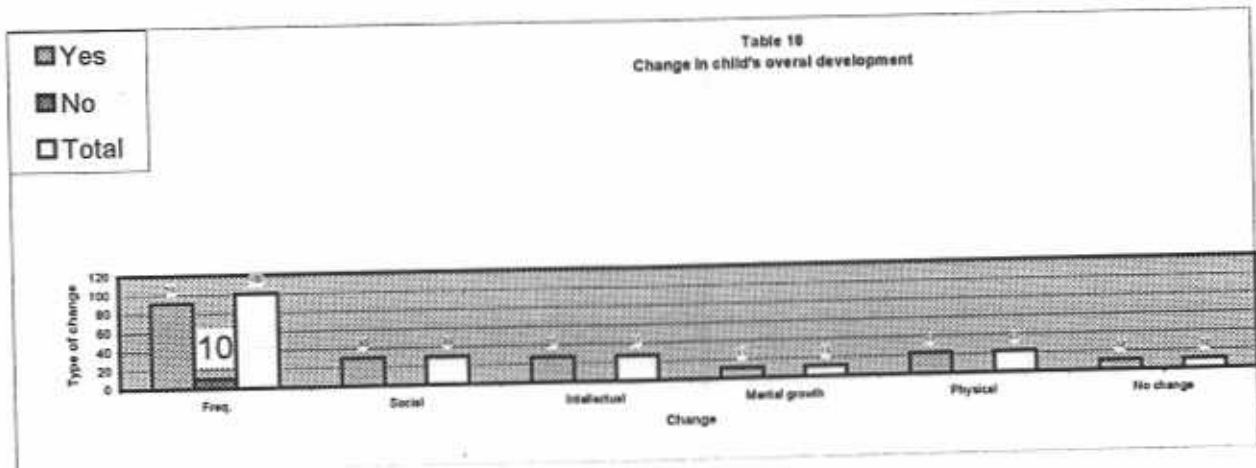


Table – 18 shows the change and type of change in mentally retarded children. 90% children were changed after admission in school. 90/100(90%) children showed positive changes and 10/10(10%) showed no progress. Out of 100 children 30/100(30%) mentally retarded children become social, they took part in class and home activities and mix up with other people. 27/100(27%) children showed improvement in intellectual, they understand many things and try to do by themselves. Parents and teachers.

noticed that 11/100(11%)children's I.Q level increased,they understand the events,solve puzzles and took more interest in school activities.Physical improvement was seen in 22/100(22%)children.They try to do work by themselves.

**Table – 19: Identification Of Disability In Child**

Symptoms	F	Percentage
Perception	34	34%
Motion	27	27%
Speech	14	14%
Reflexes	25	25%
Total	100	100%

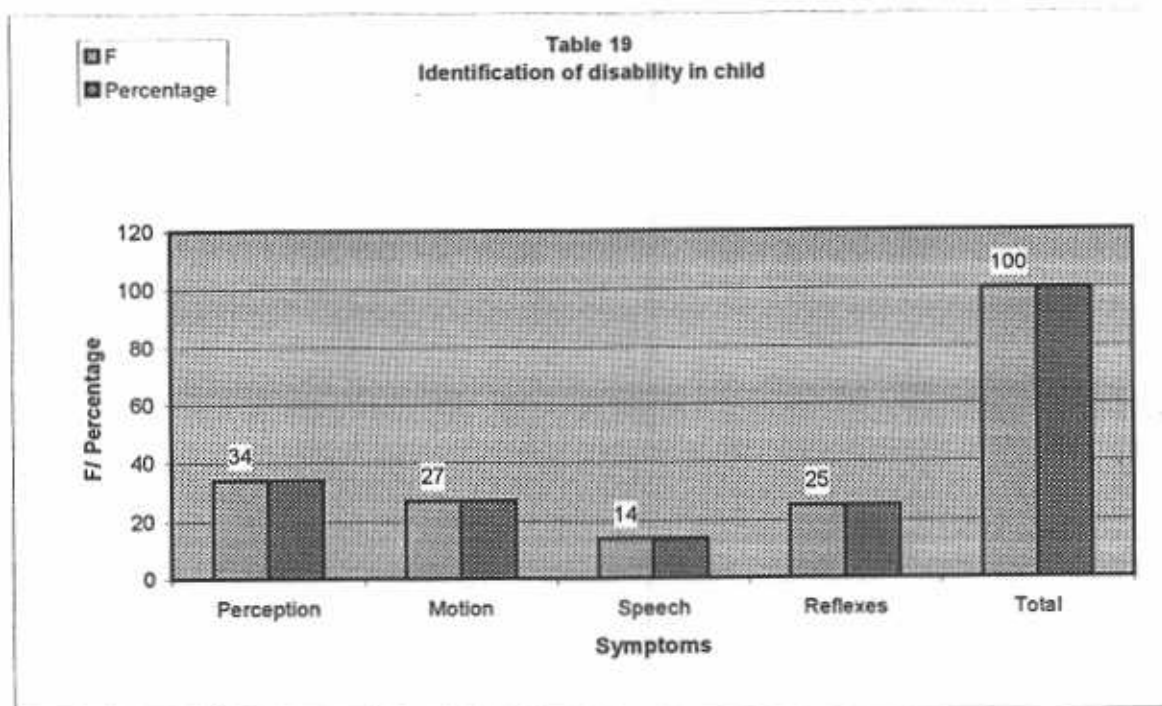


Table 19 shows the symptoms of disability in children. Researcher identifies the further disabilities in mentally retarded child through observation and from their parents. From 100 children 34/100(34%) were not perceiving the things correctly. 24/100(24%) children found disabled motor mobility. 14/100(14%) children's perception was not good, they were not able to perceive the things as they were. 25/100(25%) mentally retarded children's reflexes were not good.

**Table – 20: Postnatal Medical Care**

Contacted	F	Percentage
Yes	89	89%
No	11	11%
Total	100	100%

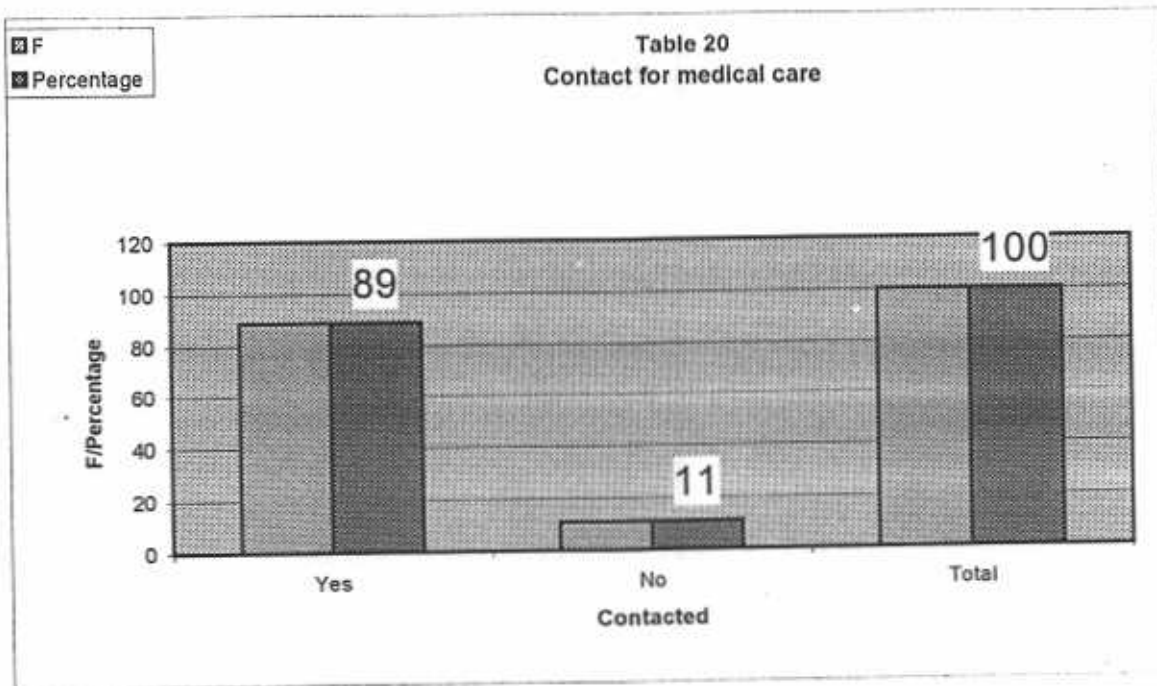


Table – 20 shows that did respondent contact any consultant for child’s medical care. Out of 100 respondents 89% respondents contact the consultant and 11% did not consult any one.

**Conclusion:**

89% respondents contacted the consultant and 11% did not consult any consultant for the retarded child’s treatment.

**Table – 21: Feelings Of Mother Towards Child**

Feelings	F	Percentage
Guilty	2	2%
Shame	5	5%
Depressed	93	93%
Total	100	100%

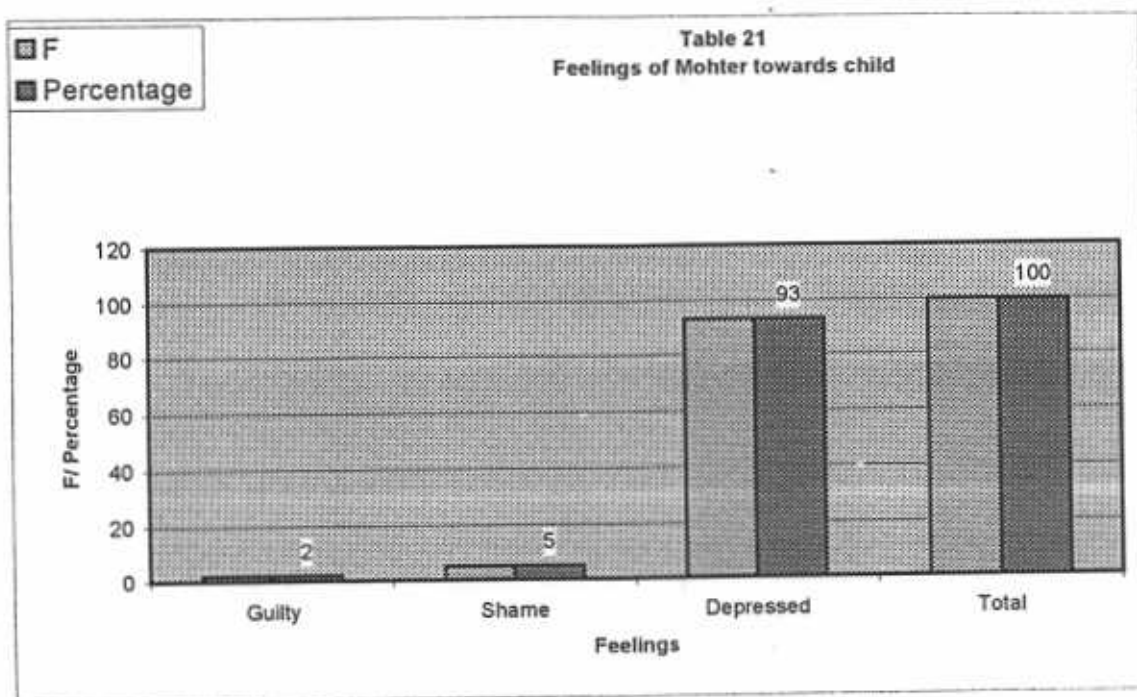


Table – 21 explains feelings of mother towards their mentally retarded child. Out of 100 respondents 2 feel guilty, and blame themselves for child's disability 5% mothers feel shame for mental retarded child and 93% feel depression.

**Table – 22: Family Attitude Towards Disabled Child**

Attitude of family	F	Percentage
Depressed	19	19%
Dislike child	15	15%
Blame mother	1	1%
Make fun of child	1	1%
No reaction	46	46%
Total	100	100%

F  
 Percentage

**Table 22**  
Family attitude towards disabled child

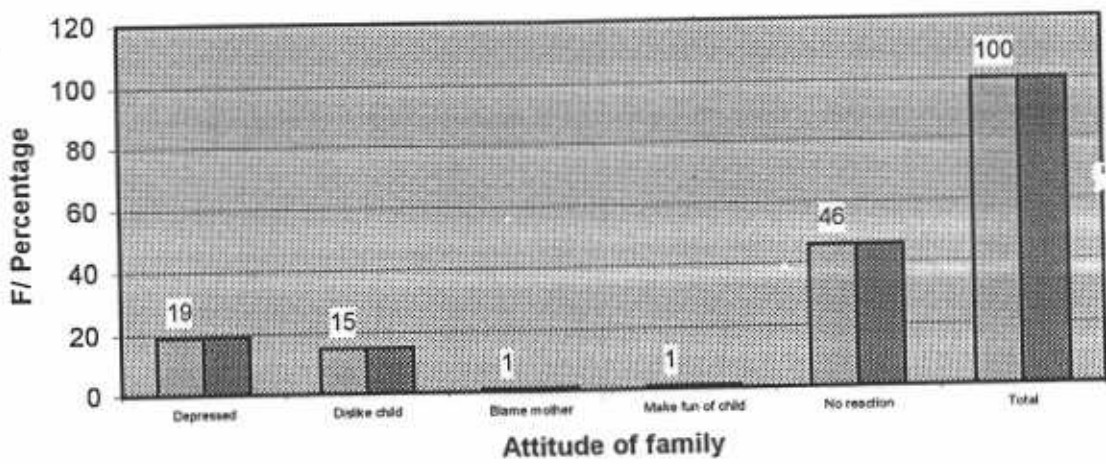


Table – 22 explains the family attitude towards disabled child. 19 families feel depression for their mentally retarded child 15 family members dislike the child they ignore him/her and never introduce him to the visitors one family blame mentally retarded child's mother for retardation. one family's member's make fun of the child and its mother and pass comments on them. 64/100 (64%) mentally retarded child's families accepted the child and did not showed any reaction at the birth of mentally retarded child.

## Section – II: Personal Profile Of The Neighbours

Table – 1: Sex Wise Distribution Of The Respondents

Sex	F	Percentage
Male	26	26%
Female	74	74%
Total	100	100%

Table 23  
Sex wise distribution of the target mentally retarded's

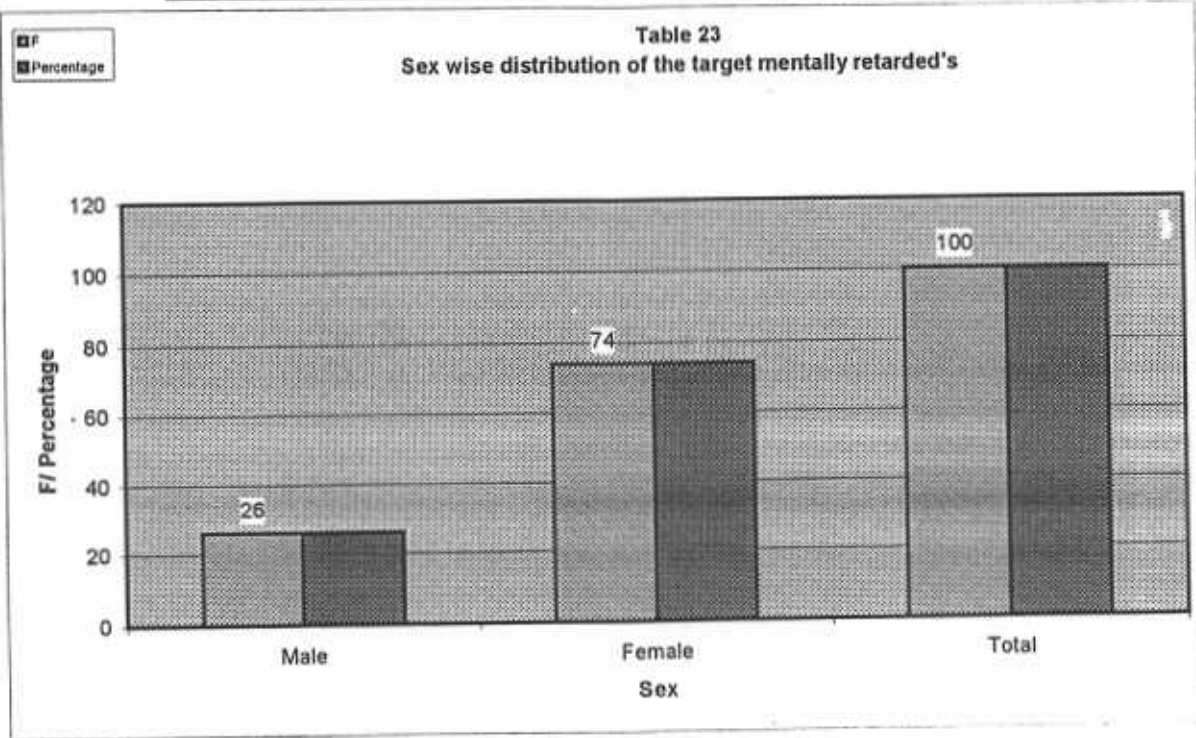


Table – 1 explains the Mentally Retarded Child's neighbours sex wise distribution. One hundred next door neighbours of mentally retarded child's were picked as respondents for research. Out of 100 respondents there were 74/100 (74%) female's and 26 were male respondents.

**Table – 2: Education And Occupation Wise Distribution Of The Respondents**

Education	F	Occupation			
		Housewife	Govt. job	Private job	Profession al
Illiterate	40	40	-	10	-
%	40%	40	-	10%	-
Primary	5	5	-	3	-
%	5%	5%	-	3%	-
Middle	5	4	-	-	-
%	5%	4%	-	-	-
Matric	25	6	5	5	-
%	25%	6%	5%	5%	-
F.A	12	2	1	1	-
%	12%	2%	1%	1%	-
B.A	10	2	2	2	-
%	10%	2%	2%	2%	-
M.A	2	4	3	3	-
%	2%	4%	3%	3%	-
Professional	1	1	-	-	-
%	1%	1%	-	-	-
Total	100	65	11	23	-
%	100%	65%	11%	23%	-

- F
- Housewife
- Govt. job
- Private job
- Professional

**Table 24**  
Education and occupatio wise distribution of the respondents

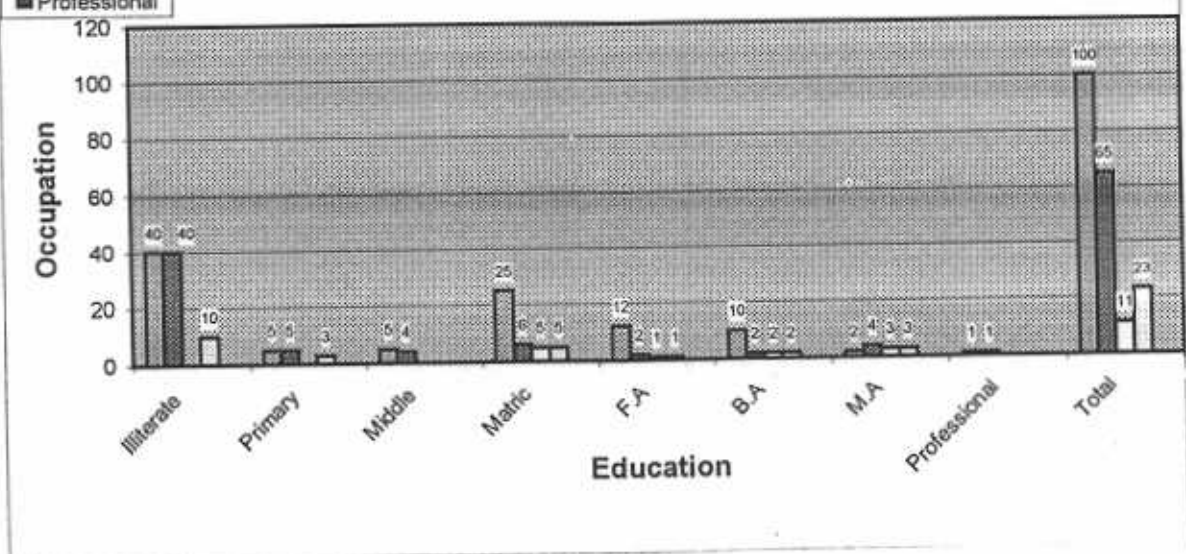


Table – 2 explains the education and occupation of the respondents. From 100 respondents 40% were illiterate and those were house wives 5/100 (5%) respondents education level was primary and those were also house wives, 5% respondents education level was middle out of them 4% were house wives and 1% was doing private job, 25% respondents were matric, out of 25 matric respondents 6% were house wives, 5% were doing government jobs and 14% were doing different private jobs. From 100 respondents 12% respondent's education level was FA, from those 2 were house wives, 1 was doing government job and 9 respondents were doing private jobs. 2% responds education was MA and they were doing government jobs. 1% respondents education was professional but the respondents was house wives because of her mentally retarded child. When question was asked why she is not doing job. She stated that I want to give my full attention to my child. If I will do job my child will be neglected. Most of the respondents were illiterate and only one was professional.

**Table – 3: Knowledge About The Reasons Of Mental Retardation**

Reasons	F	Percentage
Heredity	13	13%
Family marriage	9	9%
Tensions	3	3%
Poor diet	0	0%
Drugs	2	2%
Accident	5	5%
Don't know	68	68%
Total	100	100%

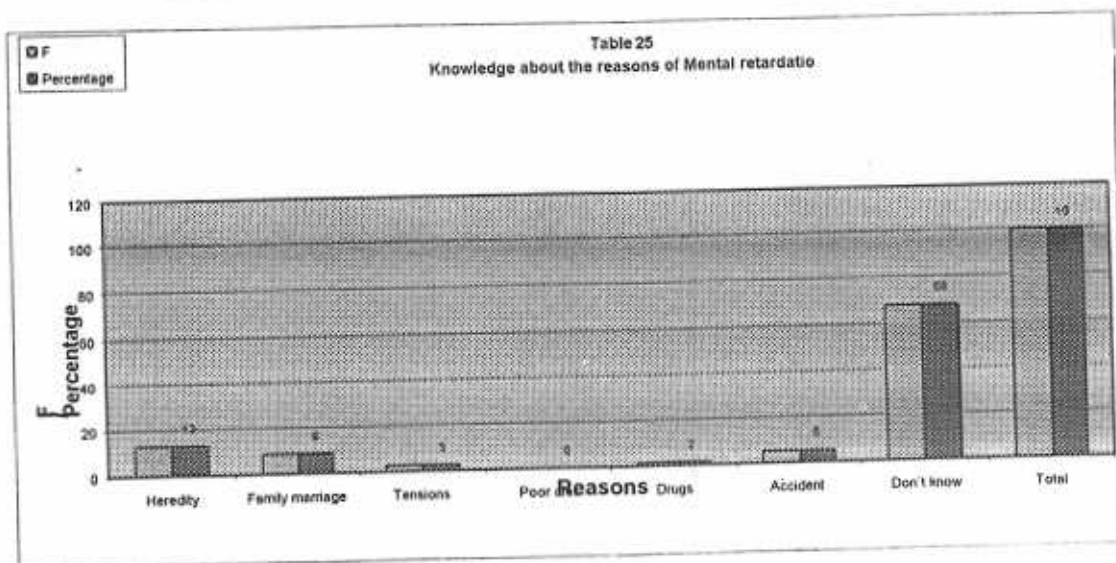


Table – 3 explains the respondents knowledge about the reasons of mentally retardation from 100 respondents 68 respondents had no knowledge about the reasons of mental retardation, but 13% respondents said heredity is the cause of mental retardation, 9% respondents said interfamily marriages are the main cause of mental retardation, 3% respondents said, during pregnancy if mother's got tensions and worries, her child effects by her mental state and she gave birth to

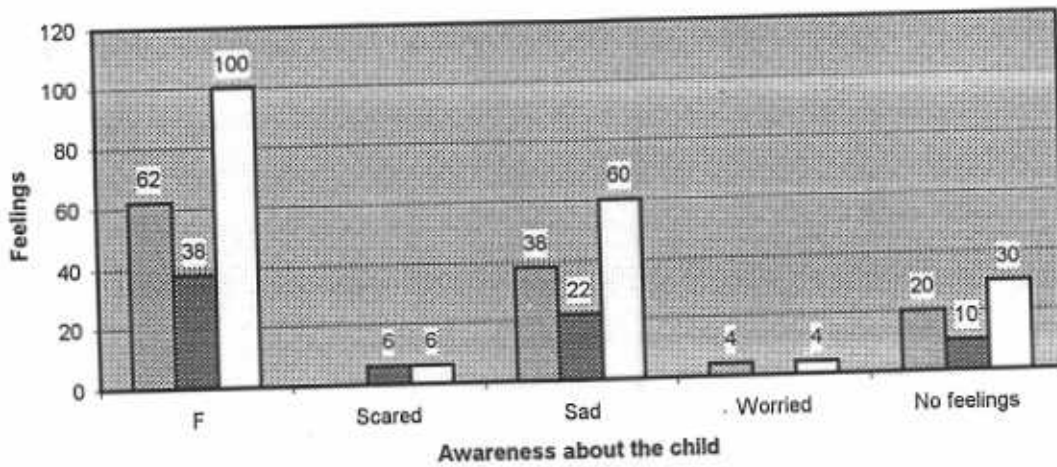
mental retarded child. 2% respondents said if during pregnancy mother took relaxation medicines or anti-biotic, these medicines effect on fetus brain. Out of 100 respondents 5% said during pregnancy if mother got injury or trauma her baby also effects by the accident.

**Table – 4: Awareness About Mentally Retarded Child Living In Neighbor And Feelings About Him**

Awareness about the child	F	Feelings			
		Scared	Sad	Worried	No feelings
Knowledge	62	-	38	4	20
%	62%	-	38%	4%	20%
No knowledge	38	6	22	-	10
%	38%	6%	22%	-	10%
Total	100	6	60	4	30
%	100%	6%	60%	4%	30%

**Table 26**  
Awareness about mentally retarded child living in neighbor and feelings about him

Knowledge  
 No knowledge  
 Total



The table - 4 shows the awareness and feelings about mentally retarded child living in neighborhood. It was in the knowledge of 62% respondents that they had a mentally retarded child in their neighbor 38 respondents had sad feelings and 4 were worried about the child. 38% respondents don't know about the child but when they heard about the child 42 respondents showed sad feelings. 6 respondents were scared and 10 showed no feelings about the mentally retarded child.

Majority of the respondents know about the retarded child living in neighbor but few did not know about the child.

**Table – 5: Give Permission To The Children To Mix-Up With Retarded Child And Think This Child Adversely Effects On Respondents Child**

Give permission to mix-up with mentally retarded child	F	%	Adverse affect of mental retardation on respondents child		
			Yes	No	%
Let the child play	91	91%	-	91	91%
Do not let the child play	9	9%	9	-	9%
Total	100	100%	9	91	100%

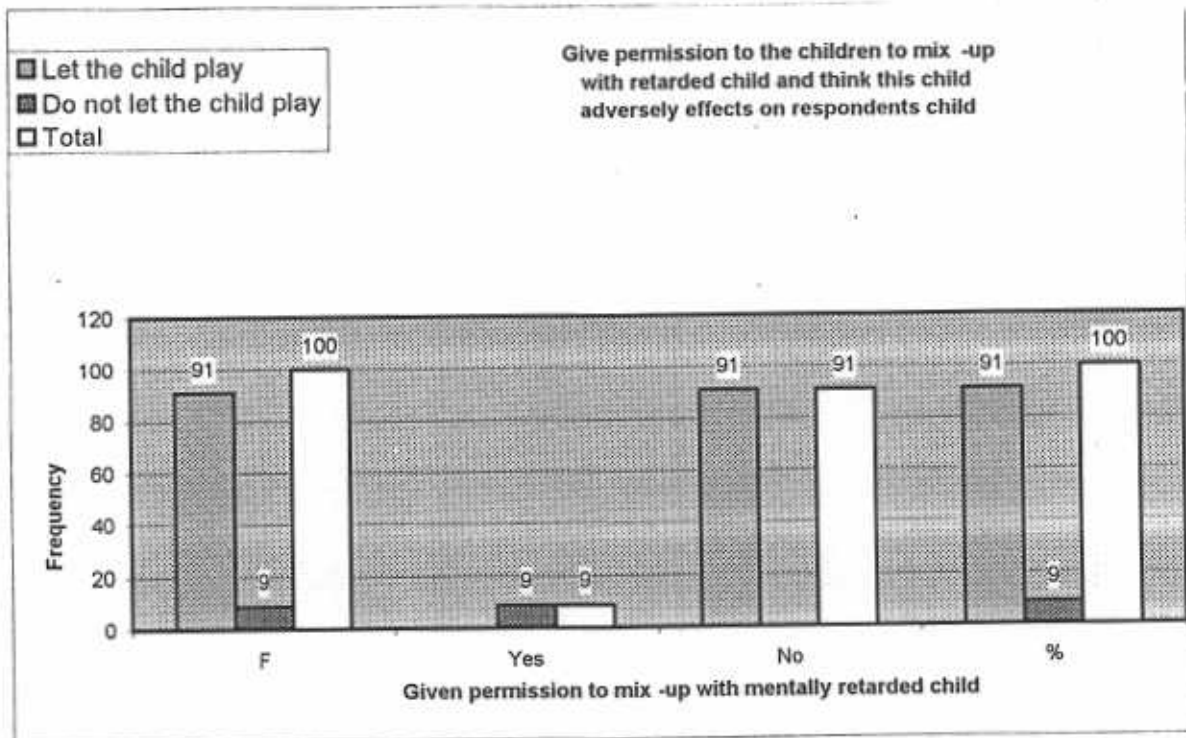


Table – 5 shows that how many neighbours / respondents give permission to their children to play and mixup with Mentally retarded child and how many did not permit their children. It further shows respondents fear why they don't give permission to their children to mix up with retarded child.

From 100 respondents 91% respondents let their children to play with mentally retarded child. They were not scared, but 6% respondents were scared of mentally retarded child because they thought if their children plays with mentally retarded child they will also become retarded. Moreover they stated that mentally retarded child can give norm to their children.

**Table – 6: Social Contacts Of The Respondents With The Mentally Retarded Child's Family**

Social contacts	F	%	Reasons for having no contacts				
			Scared	Heredity	Due to stigma	Did not explain	%
Do have	23	23%	-	-	-	-	23%
Do not have	77	77%	-	8	9	-	77%
Total	100	100%	0	8	9	83	100%

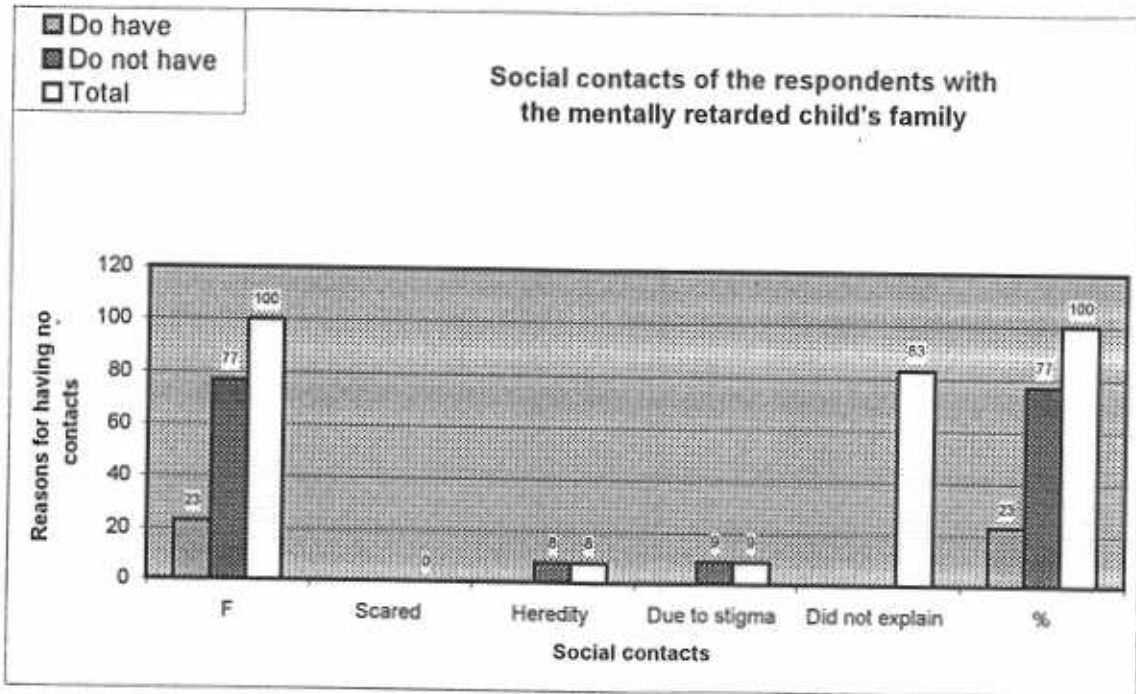


Table – 6 explains the social contacts of respondents with the mentally retarded child's family. Out of 100 respondents 23% respondents had the social contacts with mentally retarded child's family because they were not scared and had no objection to made family relations. 77% respondents don't had social contacts with mentally retarded child's family because they were scared of stigma the people give such families. They were afraid if we make contacts and relations with mentally retarded child's family people will also give them stigma. 8% people said if we make relations or married with such family the newborn can be effected through heredity factor.

**Table – 7: Assistance And Suggestions To The Effected Family**

Assistance to the mentally retarded child	F	%	Suggestions		
			Yes	No	%
Assist the child	23	23%	20	3	23%
Did not assist the child	77	77%	12	-	77%
Total	100	100 %	32	68	100%

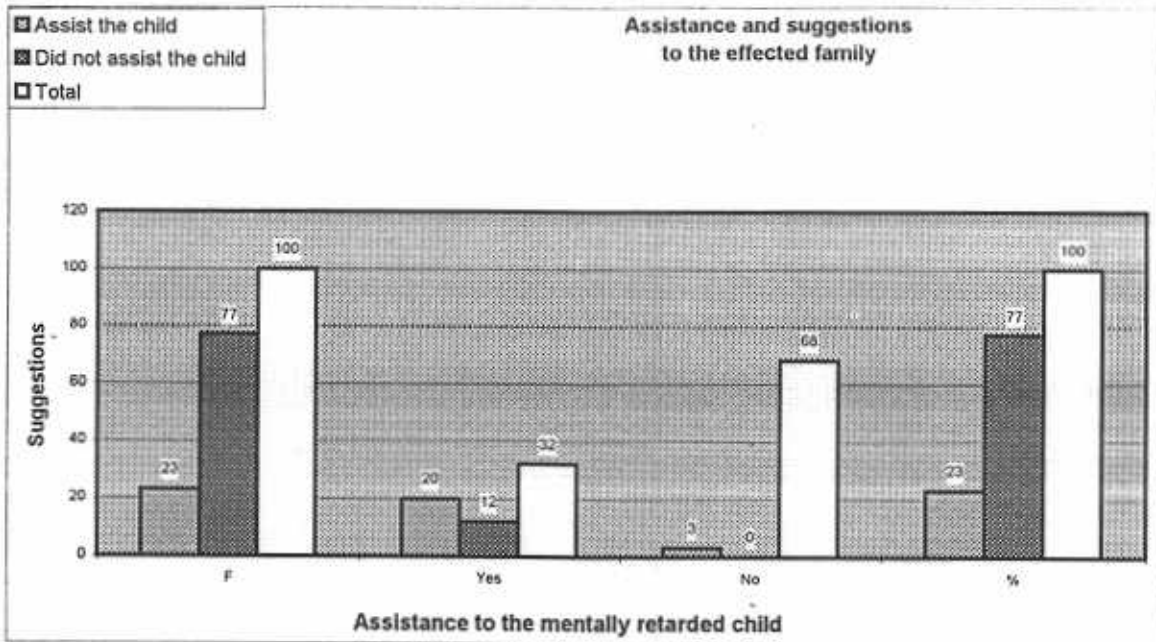


Table – 7 shows that respondents give assistance and suggestions to the mentally retarded child's family. 23% respondents give assistance to the child and give suggestions to his family. They had good family relations. They oftenly take care of mentally retarded child's in the absence of the family. 77% did not assist the child and 12% give suggestions to the parents of mentally retarded child. 68% respondents did not give any suggestions to the parents of retarded child. They said we are afraid if we give them suggestions they will mind it because they are very sensitive and don't want to talk about their child's disability.

**Table – 8: Family Members Attitudes Towards Mentally Retarded Child**

Family members	F	%	Attitudes			
			Good	Ignore	Normal	%
Grand parents	25	25%	20	2	3	25%
Parents	53	53%	40	4	9	53%
Siblings	22	22%	18	-	4	22%
Total	100	100%	78	6	16	100%

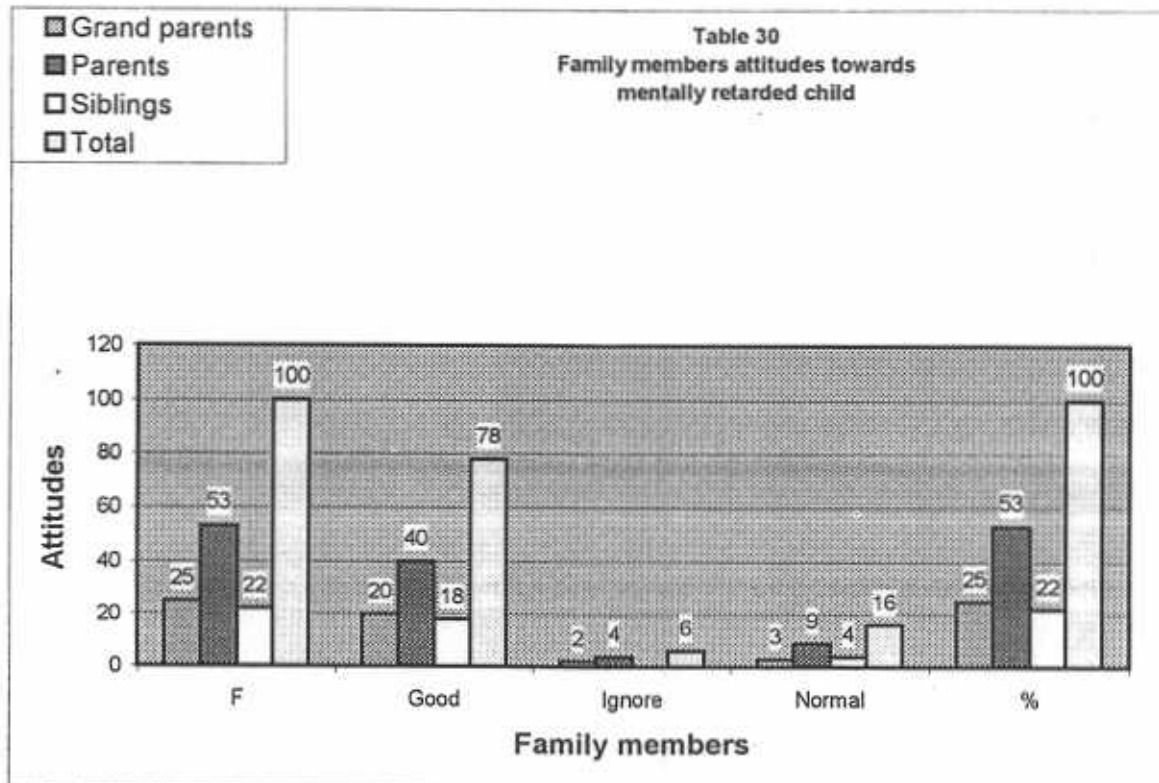


Table – 8 explains the observation and views of neighbours about mentally retarded child's family member's attitude towards their mentally retarded child's respondents said out of 100 mentally retarded children's families 25% grandparents look after the mentally retarded child's, 20% grand parents attitude was good with children 2% grand parents ignore and dislike the child, 3% grand parents shows no feelings for mentally retarded child's. Further they said 53% parents take care of their children by themselves, whom 40% parents attitude is good with their children, 4% ignore their children and not look after them properly and 9% behave normally.

22% siblings look after the child, out of 22%, 18% siblings behaviour is good with children and 4% shows no feelings for mentally retarded children.

**Table – 9: Feelings Of The Family**

Family members	F	%
Sad	52	52%
Guilty	8	8%
Depressed	40	40%
Total	100	100%

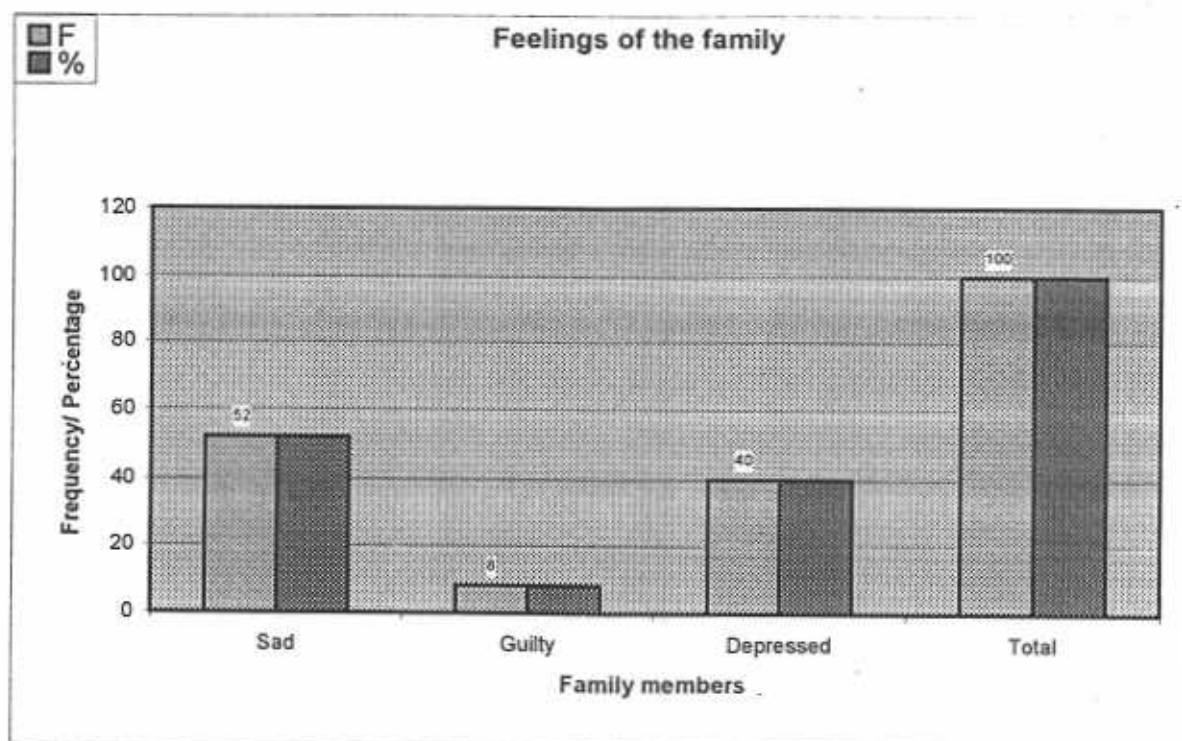


Table – 9 explains the feelings of the family towards the mentally retarded child's, 52% family members were sad about their child, because of his/her disability. They were worried about its future. 8% families had guilt feelings, about the child. They said the birth of mentally retarded child shows our forefather's or our sins. 40% families were depressed for their mentally retarded child's. They said after the birth of this child we never feel happy.

*CHAPTER - 5*

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*CONCLUSIONS*

## Chapter – 5

### Conclusions

#### A/ Conclusion Of Mentally Retarded Child's Profile

In mentally Retarded child's profile table-16 shows the Gender & Age profile of the child. From 100 children 77% children were male and out of 77%, 45% were in the age group, 5-10 years age group, 21% were between 10-15 and 11% were above 15 years of age. Regarding data about females 23% were female out of 23%, 10% were in 5-10 years age group. 9% were in 10-15 years and 4% were above 15 years. Table-17 shows the types of mentally retardation found among children, out of 100 children 25% were slow learner, 25% had multiple mental retardation, 21% had complete mentally retarded, 17% had Down's Syndrome and 12% children had Cerebral Palsy. Table-18 shows the change in child's over all development. 90% parents feel change in their children 30% children were socially, 27% intellectually. 22% physically changed and 11% children's mental growth was increased. 10% children showed no change.

#### Mentally Retarded Child's Profile (Finding)

- Out of 100 children 77% were male and 23% were female.
- Out of 77% male 45% were in 5-10 years age group 21% were in 10-15 and 11% were in above 15 years age group.
- Out of 23% female 10% were in 5-10 years age group. 9% were in 10-15 years and 4% were above 15 years.
- 25% children were slow learners.
- 25% children had multiple mental and physical diseases.
- 21% were completely mentally retarded.
- 17% were Down's Syndrome.
- 12% had Cerebral Palsy
- 90% children showed change in their over all development only 10% did not show any change.
- 30% children showed social change.

- 27% children showed intellectual change.
- 22% children showed physical change.
- 11% children showed positive change in mental growth.

## **B/ Conclusion Of Mother's Profile**

1. **Personal Profile:** Personal profile of the mothers shows the age of mothers. Table – 1 shows the age of mothers which ranged from 20 to 60 years, majority of them i.e. 43% among them were between 40-50 years and 3% were between 20-30 and above 60. Table – 2 shows the educational status of mothers, 72% mothers were illiterate only 1% were professionally educated, table – 3 shows 88% respondents were housewives and 1% was doctor, table – 4 shows 46 respondents were Pathans and 3% were Hazarawai.
2. **Socio-Economic Profile:** Table – 5 shows the socio-economic status of mothers, 50% respondents belonged to middle class and only 10% belonged to upper class. Table – 6 shows the family structure and family size of the respondents, 62% respondents lives as nuclear family and their family size was between 1-10, only 6% families were living as extended families. Table-7 shows the education and occupation of respondents spouse, 31% spouse were illiterate and 4% were post-graduate, table-8 shows the marriage pattern of the respondents, according to the informations obtained families of 79% respondents practiced endogamy while 21% families practiced exogamy.
3. **Social Factors Profile:** In Social factors profile table-9 shows the age of the respondents at marriage time and at the birth of child, 66% mothers age at the marriage time was between 15-20 years and at the birth of child their age was between 15-30 years. Only 1% age at marriage time was 30-35 years and only 1 mother's age was above 40 at the child's birth. Table-10 shows the respondents married life pattern 72% respondents spouse behaves nicely with them and they were happy with their spouse. Only 4% were not happy with

their spouse because they give them physical and mental tortures. Table-11 shows the disease of respondents during pregnancy and medication, 6% got different diseases. Table-12 shows the diet of mothers during pregnancy. 63% mothers took balanced diet. Table-13 shows the place and type of delivery. 68% mothers give birth their retarded child at home and the children were delivered normally, 27% mothers give birth their children at hospital only 1% child was delivered by seizer and 2 were delivered by instruments.

4. **Psychological factors Profile:** In Psychological factors profile table-14 shows the family relations and acceptance of pregnancy. 48% mothers relations were good and they accepted pregnancy happily only 8% mothers relations were not good out of 8%, 4% accepted pregnancy happily and 4% did not, table-15 shows the feelings and choice for pregnancy. 46% mothers were depressed during pregnancy out of 46%, 44% wanted to keep the pregnancy but 2% wanted to abort the child. 42% were worried out of 42, 41% want to keep the pregnancy and only 1% wanted to abort it, 11% were worried, out of 11%, 10% wanted to keep and 1% wanted to abort the child. The mothers were depressed and worried because they had retarded children in their family and they don't want more retarded children.
5. **Mentally retarded child's Profile:** Table -16 shows the gender and age of the child. Majorities of the children were male children their age was in between 5-10 years. Females were less than male children. Table-17 shows the types of mental retardation found in children most of the children got multiple diseases and slow learning. Table-18 shows the change and type of change in child. 90% children showed change, 30% showed social, 27% intellectual, 11% in mental growth and 22% showed physical change, only 10% children did not showed any change.
6. **Awareness about disability of child:** Table-19 shows the identification and symptoms of disability in children. 34% children did not perceive the things

accurately, 27% children's motions, 25% children's reflexes and 14% children's speech were not clear table-20 shows the consultant consulted for children. 89% respondents consulted the consultant for medical care of their children.

7. **Family attitudes towards disabled child:** Table-21 shows the feelings of mother towards her mentally retarded child, 93% mothers were depressed, 5% feel shame and 2% feel guilty for their child. Table-22 shows the family attitude towards mentally retarded child, 46% family members showed no reaction, 19% feel depression, 15% dislike the child, 1% blame the mother for child's retardation and 1% make fun of the child.

### **Mother's Profile (Findings)**

- Out of 100 respondents mothers present age range was between 20-60.
- 72% mothers were illiterate and only 1% was professionally educated.
- 88% mothers were house wives and only 1 was Doctor.
- 46% mothers were Pathans and only 3% were Hazarawai.
- 50% respondents belonged to middle class only 10% belonged to upper class.
- 62% respondents lives as nuclear family and their family size was between 1-10 and only 6% families were living as extended families.
- 31% respondents spouses were illiterate and 4% were post-graduate.
- 79% respondents practiced endogamy and 21% exogamy.
- 66% respondents age at the time of marriage was between 15-20 years. Only 1% mothers age at marriage time was between 15-30.
- 59% mothers age at the time of mentally retarded child was in between 15-30. Only 1% mothers age was above 40.
- 72% respondents spouse behaves nicely with them and they were happy with their spouse.
- 4% respondents spouses did not behave nicely and they were not happy, because they give mental and physical tortures to the respondent.
- 6% mothers look balance diet during pregnancy.

- 68% mothers give birth their retarded child at home and the children were delivered normally.
- 27% mothers give birth their retarded child at hospital normally only one child was delivered by seizer. Only 2 children delivered by instruments.
- 48% mothers accepted pregnancy happily and their relations were good with family members.
- 46% mothers were depressed during pregnancy and they wanted to keep the pregnancy. On 4% mothers want to abort the child.
- 11% mothers were worried during pregnancy and want to keep the pregnancy.
- 77% children were male and 23% were female. Age group of children was between 1-15.
- Most of the children were in 5-10 years age group.
- 25% children were slow learners.
- 25% children had multiple diseases.
- 17% children had Down's Syndrome disease.
- 12% children had Cerebral Palsy.
- 90% children showed change. 30% children showed social 27% intellectual, 11% in mental growth and 22% showed physical change.
- 10% children did not showed any change.
- 34% children did not perceive things accurately.
- 27% children's motion 25% children's reflexes and 14% children's speech was not clear.
- 89% respondents consult the consultants for their children.
- 11% respondents did not consult any consultant.
- 93% mothers were depressed for their mentally retarded child.
- 5% mothers feel shame for their retarded child.
- 2% mothers feel guilty for their retarded child.
- 46% family members showed no reaction for mentally retarded child.
- 19% family members feel depression for the child.
- 15% family members dis-like the child.
- 1% family members blame the mother for retarded child's birth.
- 1% family members make fun of the child.

## C/ Conclusion Of Neighbor's Profile

- 1. Personal Profile:** of the respondents who were the neighbors of the families having mentally retarded child. Table – 23 and table – 24 shows that most of the respondents were female which were 74% and male were 26%. Out of 74% female respondents majority (65%) of female were housewives and illiterate. Over all respondents education level was very low only 25% were Matric, 12% were F.A., 10% were graduates only 2% were post-graduates and 1% was from medical profession occupations wise distribution showed a wide range of difference, i.e. 65% were the housewives, 23 were doing the private jobs and only 11 had government job.
- 2. Social Profile:** Table – 25 regarding social relations and contacts show that most of the respondents who were 68% didn't know the reasons of mental retardation. The respondents who had the knowledge were 13% gave heredity and the reasons gave by others were that family marriage, tensions, drugs and accidents were the reasons of mental retardation. Regarding awareness and feelings about the child 62% had the knowledge about mentally retarded child living in their neighbor. The respondents who had the knowledge 38% had sad feelings, 4% were worried about child's future and 20% had no feelings about the child. 38% respondents who had no knowledge about the child, when they heard about the mentally retarded child 6% felt scared, 22% felt sad and 10% had no feelings about the child. So the majority of the respondents had the feelings of sadness about the child and had the knowledge about him, but they didn't know the reasons of mental retardation. Table – 28 shows 23% respondents had the social contacts with retarded child's

family and 77% respondents don't want to make social contacts with such family because of the stigma and fear of abnormality so that their child may not get the problem. Table – 29 shows the assistance and suggestion to the effected family. 23% people take care of the child and out of 23% people 20% give suggestions to the parents and 3% did not give them any suggestion for the child's treatment. 77% people did not assist the child out of 77% only 12% give suggestions for child's treatment to the parents.

3. **Psychological Profile:** Table – 27 shows that majority of the respondents gave permission to their children to mix up with mentally retarded child. Only 9% did not give permission to their children. As a neighbor 23% respondents look after the child in the absence of their parents and they usually gave suggestions to the parents for the well being of the child, and 77% did not take care of the child. Table – 30 shows the over all attitudes of the family all parents, Grand parents and Siblings was good with the child only 6% ignored the child. Table – 31 shows the feelings of the parents having mentally retarded child majority of the parents were sad for their child 40% were very depressed and 8% had guilt feelings about their child.

#### **Neighbours Profile: (Findings)**

- Out of 100 respondents 26% were male and 74% were female. So the female respondents were more than male respondents.
- Literacy rate shows that 40% respondents were illiterate, 5% were educated at primary level, 5% were at middle level, 25% were Matric, 12% were F.A., 10% were B.A. 2% were M.A. and one was professionally educated.
- 65% respondents were housewives, 3% were teachers, 8% were doing government jobs, 23% were doing private jobs and one was doing professional job.

- 13% respondents give the reason of mental retardation heredity, 9% give reason family marriage, 3% told tension, 2% said drugs, 5% said accidents and 68% don't know the reasons of mental retardation.
- 62% respondents had the knowledge about the child living in neighbor out of 62% respondents 38% feel sad and 4% were worried about that child and 20% had no feelings, 38% respondents don't have the knowledge out of them 6% were scared, 22% feel sad and 10% had no feelings about the mentally retarded child.
- 91% respondents give permission to their children to play with that child and they said the retarded child will not effect their children but 9% did not give permission to their children to play with that child because they thought the retarded child will affect at their children.
- 23% respondents had social contacts with retarded child's family and they don't have any objection to make relations with such family but 77% don't have social contacts and they don't want to make relations with such family 23% respondents give assistance to the child and give suggestion for child to the family but 2% did not gave suggestions, 77% did not assist the child they give suggestions to the family.
- The family members which look after the child were 25% Grand parents 20% were good with the child 2% ignore and 3% respondents behavior was normal. 53% parents by self take care of the child 40% parents attitude was good, 4% ignores the child and 9% behaves normally. 22% siblings take care of the child 18% were good and 4% ignored the child.
- 52% family members feel sad, 8% guilty and 40% feel depressed about the child.

## SUMMARY

Mental retardation is one of the social problems the world over. According to WHO 10% of the world population suffers from disabilities among which 3% are mentally retarded.

In Pakistan the magnitude of the problem is 2.49% of the total population according to 1998 Census of Population.<sup>7</sup> This accounts for about 3.75 million disabled in Pakistan out of this number 14% of the total is disabled which means 0.9525 million persons.

This is quite significant number and is a challenge to meet. Why disabilities are caused, is a question of multifact resources including Bio-medical, social, and Physiological.

In order to find out the causative factors of disabilities, this empirical study was conducted in NWFP and Balochistan provinces of Pakistan. The two most backward and poor provinces of the country.

It was find out that genetics, accident, diseases of post-natal, environmental hazards and self medication were found to be the causes among many respondents. The rest of this can be found in the research work..

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<sup>7</sup> Government of Pakistan, National Policy for Special people, Islamabad, Ministry of Women Development and Social Welfare & Special Education, 2005. p.3.

*CHAPTER - 6*

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*RECOMMENDATIONS*

## Chapter – 6

### Recommendations

All religions recommend to take care of special people and give them love and affection some should obey religion.

- Genetic counseling and treatment is very important if the parents desire for other child.
- Improvement of preventive measures before conception, during pregnancy and at the time of delivery is needed.
- More trained and qualified teachers are required.
- Government should take more interest in special education schools.
- Treatment and services should be free of cost for the disables by the government.
- During preparing rehabilitation plan the I.Q (intelligence quotient) and physical ability should be kept in mind.
- Iodine, Vitamins, Iron, Protein and other minerals should mix in infants foods & growing children's supplements.
- Doctors should avoid to recommend antibiotics to pregnant women and unnecessary exposure to harmful X-rays.
- A pregnant mother should avoid self-medication.
- A pregnant mother should take balanced diet.
- After the age of forty mothers should avoid to give birth to more children.
- Training given to the retarded must be practical. While preparing the treatment and rehabilitation plan, parents, therapists, doctors, psychiatrists, teachers and social workers should be consulted.

- The social NGO's should keep in touch with each other and quarterly meeting should be held regularly it would save duplication of labour and expenses.
- At least a special education centre should be established in every district.
- Special training should be provided to interested people, who have soft corner for special children and want to serve in this sector.
- Training should be provided to the parents on regular basis.
- Social awareness should be created among the people to accept the special people as part of the society.
- Employment opportunities should be given.
- Sheltered workshops, institutions and trained staff is needed in every city.
- The products produced by the disabled people in workshops/institutions should be introduced and sold in the market.
- Encouragement of the parents of special children is very necessary.

*ANNEXURE*

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*INTERVIEW SCHEDULE  
GLOSSARY  
&  
BIBLIOGRAPHY*

## Interview Schedule

(For The Mothers Of Mentally Retarded Child)

### Personal Information

Respondent No. \_\_\_\_\_

1. Age: \_\_\_\_\_
2. Education: \_\_\_\_\_
3. Occupation: \_\_\_\_\_
4. Class: \_\_\_\_\_
5. Cast: \_\_\_\_\_
6. Blood group of Husband \_\_\_\_\_ Wife \_\_\_\_\_

### Family History Information

7. Number of family member. \_\_\_\_\_
8. Family System:  
Nuclear \_\_\_\_\_ Joint \_\_\_\_\_ Extended \_\_\_\_\_
9. Education of Husband?  
Illiterate \_\_\_\_\_ Primary \_\_\_\_\_ Middle \_\_\_\_\_ Matric \_\_\_\_\_  
F.A. \_\_\_\_\_ B.A. \_\_\_\_\_ M.A. \_\_\_\_\_ Other \_\_\_\_\_
10. Occupation of Husband \_\_\_\_\_
11. Is your spouse blood related to you?  
a) Yes \_\_\_\_\_ b) No \_\_\_\_\_
12. Is your husband normal in  
a) Behavior \_\_\_\_\_  
b) Mentally \_\_\_\_\_  
c) Physically \_\_\_\_\_
13. Is Mental Retardation exists in your family?  
a) Yes \_\_\_\_\_ b) No \_\_\_\_\_
14. If yes, where you found in  
a) In laws \_\_\_\_\_  
b) Respondents parents

15. If so how many retarded persons are there?
- a) 1 - 3
  - b) 3 - 4
  - c) 5 - 6
  - d) 7 - 8
  - e) 9 - 10
  - f) More than 100

### Causative Factors

16. At what age you married?
- a) 15 - 20
  - b) 20 - 25
  - c) 25 - 30
  - d) 30 - 35
17. What was your age at the birth of this child?
- a) 15 - 20
  - b) 20 - 25
  - c) 25 - 30
  - d) 30 - 35
  - e) 35 - 40
  - f) Above than 40
18. Sex of child a) Male \_\_\_\_ b) Female \_\_\_\_
19. What is the age of the child \_\_\_\_\_
20. Which type of mental disability exists in child \_\_\_\_\_
21. Are you happily married?
- a) Yes \_\_\_\_ b) No \_\_\_\_
22. When you were expecting this child how were your relations with your husband?
- Good \_\_\_\_ Bad \_\_\_\_ Satisfactory \_\_\_\_ Other \_\_\_\_
23. Did you accepted his pregnancy happily?
- a) Yes \_\_\_\_ b) No \_\_\_\_

24. During pregnancy how feel?  
Happy \_\_\_ Worried \_\_\_ Depressed, tense \_\_\_ Other \_\_\_
25. Did you try to abort this pregnancy?  
a) Yes \_\_\_ b) No \_\_\_
26. Did you got any disease during pregnancy?  
a) Yes \_\_\_ b) No \_\_\_
27. Did you got any accident?  
a) Yes \_\_\_ b) No \_\_\_
28. Did you got balanced diet during pregnancy?  
a) Yes \_\_\_ b) No \_\_\_
29. Where the child was born?  
Home \_\_\_ Hospital \_\_\_ Clinic \_\_\_ Other \_\_\_
30. How was the child delivered normally?  
a) Normally \_\_\_  
b) Low forsip \_\_\_  
c) By session \_\_\_
31. Was the Oxygen given to this child?  
a) Yes \_\_\_ b) No \_\_\_
32. Did you ever took medicines for mental retardation?  
a) Yes \_\_\_ b) No \_\_\_
33. If you mention the name of medicine \_\_\_\_\_

#### Awareness About The Disability

34. How do you realize that, your child is retarded?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
35. Is he/she retarded by birth?  
a) Yes \_\_\_ b) No \_\_\_
36. If no, how he/she became retarded \_\_\_\_\_

37. Did you met any consultant for his/her treatment?

a) Yes \_\_\_\_ b) No \_\_\_\_

38. Did your family practice inter family marriages?

a) Yes \_\_\_\_ b) No \_\_\_\_

39. In your opinion why you got retarded child?

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40. Do you know the reasons of mental retardation

a) Yes \_\_\_\_ b) No \_\_\_\_

41. If so explain \_\_\_\_\_

#### **Respondents Of Family Attitude Towards Retarded Child**

42. Did you except this child happily at birth?

a) Yes \_\_\_\_ b) No \_\_\_\_

43. How do you feel about this child now?

a) Guilty \_\_\_\_

b) Shame \_\_\_\_

c) Depressed \_\_\_\_

d) Other \_\_\_\_

44. Did the other family members accepted this child?

a) Yes \_\_\_\_ b) No \_\_\_\_

45. How was your in-laws reaction for this child?

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46. How was your husband's reaction at this child birth?

a) Was he angry \_\_\_\_

b) Did he blame you \_\_\_\_ or your family \_\_\_\_

c) Talked about divorce \_\_\_\_

- d) Other \_\_\_\_
47. Has this child affected your married life?  
a) Yes \_\_\_\_ b) No \_\_\_\_
48. Do you avoid to bring this child in contact with other people?  
a) Yes \_\_\_\_ b) No \_\_\_\_ Some times \_\_\_\_
49. In your absences who takes care of him/her?  
a) Father \_\_\_\_  
b) Grand parents \_\_\_\_  
c) Siblings \_\_\_\_  
d) Maid \_\_\_\_ Servant \_\_\_\_  
e) Other \_\_\_\_
50. Did you notice any change in child's over all development?  
a) Yes \_\_\_\_ b) No \_\_\_\_
51. If yes, what type of change?  
a) Social \_\_\_\_  
b) Intellectual \_\_\_\_  
c) Mental growth & development \_\_\_\_  
d) Physical \_\_\_\_  
e) Other \_\_\_\_

## Interview Schedule

(For the Neighbors of Mentally Retarded Child)

1. Name \_\_\_\_\_
2. Sex: \_\_\_\_\_
3. Education: \_\_\_\_\_
4. Occupation: \_\_\_\_\_
5. Address: \_\_\_\_\_

### Societies Approach/Behaviour Towards Mental Retardation & Retarded Child

6. Do you know the reasons of mental retardation?  
a) Yes \_\_\_\_ b) No \_\_\_\_
7. If yes, which:  
a)  
b)  
c)  
d)
8. Do you have any knowledge about mental retardation?  
a) Yes \_\_\_\_ b) No \_\_\_\_
9. Do you know that you have a mentally retarded child in your neighborhood?  
a) Yes \_\_\_\_ b) No \_\_\_\_
10. How do you feel about him?  
Scared \_\_\_\_ Sad \_\_\_\_ Other \_\_\_\_
11. How often you visit the child in your neighborhood? \_\_\_\_\_
12. Do you permit your children to mix-up with this particular child?  
a) Yes \_\_\_\_ b) No \_\_\_\_
13. Do you think your children will be adversely effected by this child?  
a) Yes \_\_\_\_ b) No \_\_\_\_
14. Do you think that, this retarded child is harmful to your family?  
a) Yes \_\_\_\_ b) No \_\_\_\_

15. Would you avoid to visit retarded child, a family?  
a) Yes \_\_\_\_ b) No \_\_\_\_
16. Would you like to make any relation with such type of family?  
a) Yes \_\_\_\_ b) No \_\_\_\_
17. If no, explain why? \_\_\_\_\_
18. Would you ever take care of this child?  
a) Yes \_\_\_\_ b) No \_\_\_\_
19. Did you ever suggest/advice any treatment to the parents of this child?  
a) Yes \_\_\_\_ b) No \_\_\_\_
20. As a neighbor did you ever offer your services to look after the child in the absence of his/her parents?  
a) Yes \_\_\_\_ b) No \_\_\_\_
21. Besides parents who else look after the child  
a)  
b)  
c)  
d)

#### Parents Attitude Towards Their Retarded Child

22. How do the parents interact with their retarded child?  
Good \_\_\_\_ Bad \_\_\_\_ Other \_\_\_\_
23. Do they fulfil the needs of their retarded child?  
a) Yes \_\_\_\_ b) No \_\_\_\_
24. Does they take him/her for outing?  
a) Yes \_\_\_\_ b) No \_\_\_\_
25. Do they take him/her to the doctor for his/her physical ailment?  
a) Yes \_\_\_\_ b) No \_\_\_\_

#### Psychological Effect On The Family

26. How the family feels having the retarded child?
- \_\_\_\_\_
- \_\_\_\_\_

27. How they feel when other people talked about their retarded child?

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## Glossary

1. **A.J.K** Azad Jamu Kashmir
2. **AAMR** American Association for Mentally Retarded
3. **Abandon** Freedom from inhibition
4. **Ailment** Disease
5. **Alzheimer disease** A progressive form of presenile dementia which is superficially similar to senility except that it strikes relatively early in life.
6. **Amniocentesis** A procedure in which a thin needle guided by ultrasound is inserted through the abdomen into the uterus of a pregnant women, fluids and cells withdrawn can analyzed for defects in the fetus.
7. **Asphyxia** Suffocation
8. **Barbaric** Cruel or brutal
9. **Bewilderment** Confuse utterly
10. **Bizarre** Odd or un-usual
11. **Chiropodist** Person who treats minor foot complaints
12. **Cliff** Steep rock face, along the sea shore
13. **Delinquent** Any one who commits a crime or violates a legal code.
14. **Didactic instruction** Instructional preparing to teaching.
15. **Dysfunctions** Any disruption in normal functioning.
16. **Encephalitis** Inflammation of the membranes covering the brain or of the brain itself.
17. **Etiologic** The term derives originally from the Greek. ethos meaning character or essential nature and - ology meaning study of causes of disease.
18. **Exceptional children** As used in child psychology the term refers to

both extremely talented and gifted children as well as to those having low intelligence or other learning disabilities.

Family routine task

Mental deficiency.

A genetic metabolic disorder characterized by an absence of the enzyme required for conversion of galactose to glucose.

Any of the functional units of the chromosomes. Genes manifest themselves in heredity by directing the synthesis of proteins.

The development of breasts on a male, because of hormone malfunction.

Occupation of a dwelling place

Originally, a facility for persons released from institutions. They serve as semi-protective environments for those "half way in" persons who can still function productively in the community but need a supportive caring shelter.

Water or fluid in the head. An abnormal accumulation of cerebrospinal fluid within the skull producing an enlarged head.

A cover term for any use of water in a therapeutic manner.

A deficit in secretions of the thyroid gland resulting in a subnormal metabolic rate.

Abbreviation, means intelligence quotient.

Murder of an infant.

Pertaining to the intellect or to intelligence.

Plead in favour of mediate.

Disease caused by uncontrolled over production

19. Family chore

20. Feeble – minded

21. Galactosemia (Galactose enzyme)

22. Genes

23. Gynecomastio

24. Habilitation

25. Halfway house

26. Hydrocephalus

27. Hydrotherapy

28. Hypothyroidism

29. I.Q.

30. Infanticide

31. Intellectual

32. Intercede

33. Leukaemia

of white blood corpuscles.

Insani

Middle ages

Below-average intellectual functioning as assessed by a standard I.Q. (Intelligence Quotient)

Down's syndrome

Relating to the first few weeks of a baby's life.

Nerve injured

A violent and uncontrolled display of anger.

The condition being over weight. Obesity which results from simple overeating.

Active movement.

Strange, distinct, special.

Difficult or dangerous situation.

Loosely, pertaining to mental events which have motor effect.

Rebound effect, however the meaning usually is restrict to an increase in some physiological function following a period of inhibition or deprivation.

To restore to good form or proper functioning condition. To restore to a previous condition or status.

Mild disease with serious complication. In a pregnant women's during the first two or 3 months of pregnancy, it can produce a number of anomalies including a mental retardation.

Inhabitant or language.

**34. Lunatic**

**35. Mediaeval times**

**36. Mental retardation**

**37. Mongoloid**

**38. Neonates**

**39. Neuralgic injury**

**40. Night time tantrums**

**41. Obesity**

**42. Passive movement**

**43. Peculiar person**

**44. Plight**

**45. Psychomotor**

**46. Rebound**

**47. Rehabilitation**

**48. Rubella**

**49. Scandinavian**

50. Seizure disorder	Any sudden attack of a disorder or malady.
51. Sleep apnea	Cessation of breathing. Typically temporary in nature, because of lowered carbon dioxide levels.
52. Somatogenic disorder	Non neurological disorder. Disorder of the body. Organic disorder.
53. Spartan	Strict
54. Spinabifida	Spinal disease.
55. Sterilization	Unable to produce offspring. Surgical removal of the tests or ovaries.
56. Stigma	Mark of social disgrace.
57. Stress	Tension or strain
58. Sub-average	Under or below average
59. Superstitious	Any notion or belief held in the absence of what one not holding that notion or belief would consider to be adequate evidence to substantiate or support it sufficiently to maintain such belief.
60. Syndrome	Combination of symptoms indicating a particular disease.
61. Tabularasa	Latin meaning blank tablet or blank state.
62. Thyroid	An endocrine gland located at the base of the neck. The secretions of the thyroid control general metabolism and are important in the regulation of growth.
63. Toxic	Poisonous
64. Traits	Generally, any enduring characteristic of a person that can serve an explanatory role in accounting for the observed regularities and

consistencies in behavior.

**65. Trampoline**

Tough canvas sheet attached to a frame by springs, used by acrobats.

**66. Variables**

That which changes, that which is subject to increases and or decreases over time in short, that which varies. Variables is taken some "thing" that under goes changes.

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