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# Psycho-social Correlates of Mental Retardation: A Study of Some Selected Cases

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University of Rajshahi

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**PSYCHO-SOCIAL CORRELATES OF MENTAL  
RETARDATION: A STUDY OF SOME  
SELECTED CASES**



*Thesis submitted for the degree of  
Doctor of Philosophy*

**Sabina Sultana**

**Department of Psychology  
University of Rajshahi  
September 2004**

*Dedicated  
To  
My Parents*

*Professor Anwarul Hasan Sufi*

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## Certificate

Certified that the thesis entitled **Psycho-Social Correlates of Mental Retardation: A Study of Some Selected Cases** has been completed by Sabina Sultana, Assistant Professor of Psychology, University of Rajshahi, under my supervision and I recommend examination of the thesis.

*A. Hasan*

**Professor Anwarul Hasan**  
Research Supervisor

## *Declaration*

*This thesis entitled Psycho-Social Correlates of Mental Retardation: A Study of Some Selected Cases contains no material that has been accepted for the award of any other degree or diploma in any University. The thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.*

*Sabina Sultana*  
*Sabina Sultana*

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**The authoress**

## Abstract

The researcher closely studied 144 urban and 103 rural mentally retarded persons in Bangladesh. The age of the subjects ranges between 2 and 38 years. Out of total 247 cases 165 are male and 82 are female. The subjects are of different levels of mental retardation, clinical types and socioeconomic backgrounds. The formal and the main study was done during 2000 and 2003. But the researcher closely observed and studied all developments, problems and prospects of about 100 subjects of the 247 cases from 1992 to 2003.

Health, education, employment, housing and social security of the subjects were studied through questionnaire and personal observation by the researcher herself. She has observed the subjects at the Day Centres and at their houses. She had detail discussion with the parents, siblings, neighbors, concerned physicians and professionals.

Though the main objective was to study the psycho-social correlates of mental retardation of some selected cases, the researcher studied not only the factors but also the prenatal, perinatal and postnatal development of the subjects. She studied the impact of special education and vocational training on employment and rehabilitation of the subjects. She also studied the problems and prospects of housing and social security of the subjects. Finally she compared the problems and prospects of the rural and urban mentally retarded subjects.

It was found that the rural mentally retarded persons and their family members are in better conditions compared to their urban counterparts from the psycho-social viewpoints.

The researcher does not claim that this study is depicting a total picture of the psycho-social correlates of all the mentally retarded persons and their family members of entire Bangladesh. But this work indicates the major psycho-social aspects of the mentally retarded persons, which need further attention of the concerned professionals and the government in Bangladesh.



The researcher concludes that some awareness development has already taken place in Bangladesh to uplift the quality of life of the mentally retarded persons. But without serious involvement of the government they are yet the subjects of trials and errors by different interest groups and organizations.

The constitution of Bangladesh clearly protects the rights of the handicapped persons. But yet Bangladesh government could not announce any policy program for the mentally retarded persons. The researcher strongly recommends the government to announce a National Policy for the mentally retarded persons as soon as possible.

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*Chapter-I*  
*Introduction*

# Chapter I

## Introduction

The term psycho-social correlates of mental retardation not only denotes the psychosocial factors of mental retardation but also relatively a broader term which includes psychosocial problems and prospects of the mentally retarded persons. It includes their health, education, employment, housing and social security matters. It also includes the degree and severity of all the problems related to them, their parents, their siblings and all family members.

It is not exactly known how many people in Bangladesh are mentally retarded and what are the exact problems of these persons. It is assumed that there are about three million mentally retarded persons in Bangladesh including the borderline and mild mentally retarded cases. If they have parents, siblings and children, it is estimated that at least nine million close family members are concerned in their Daily Living Activities and everyday interpersonal relations. The mentally retarded persons and their close family members comprise about 10% of the total population in Bangladesh.

Though the rights and privileges of the handicapped persons are clearly protected under the constitution of Bangladesh, practically nothing has been done by the government to uplift the quality of life of the mentally retarded persons in this country.

Though the mentally retarded persons are there in Bangladesh from the very beginning of its human settlement, the concept of 'Mental Retardation' is relatively new to the people in Bangladesh compared to the people in developed countries. Yet many well-educated person in Bangladesh confuse mental retardation with mental illness.

Practically nothing was done to uplift the life of the mentally retarded persons in Bangladesh until 1977. In 1977, Professor Dr. Sultana S. Zaman of Dhaka University

Psychology Department started an integrated special education class for the mentally retarded children inside Wills Little Flower School in Dhaka city with the help of some students of Dhaka University Psychology Department. Then she organized some parents and professionals in Dhaka city and formed The Society for the Care and Education of the Mentally Retarded Children Bangladesh (SCEMRB). Within one decade this organization could initiate some other programs in the capital city and in some other district towns of Bangladesh.

In 1982, Dr Sultana Zaman's organization SCEMRB in Collaboration with the Norwegian Association for the Mentally Retarded (NFPU) introduced a vocational education centre and sheltered workshop for the adults in Dhaka city. This centre has come to be known as the Bangladesh Institute for the Mentally Retarded (BIMR). This centre has now become a modern Institute run by the professionals for staff training, research, publication, and model centre for the Mentally Retarded persons of all ages. BIMR continues the sheltered workshop and other model special classes. Bangladesh Government has recently recognized this institute and provided grants for its development. The NGO that established this Institute promoted more than 22 branches at different places of the country, which provide day care to about 2000 Mentally Retarded persons at present.

In May 1984, Dr. Sultana Zaman promoted another NGO known as Bangladesh Protibandhi Foundation (BPF). The new NGO started functioning for the developmentally disabled children, this NGO also run one model institute with multidisciplinary professionals in Dhaka city known as 'Kalyani'. The Protibandhi Foundation has some model centres both in the urban and rural areas of the country. This organization has published several important books, journals, health education guides, etc.

In 1992, The SIVUS Institute, a Voluntary Social Welfare Agency has started functioning mainly in the northwestern part of Bangladesh. This organization provides home based counseling to approximately 700 mentally handicapped persons in many villages through the volunteers, mainly the students of Rajshahi University

and Rajshahi Medical College. The main objective of the organization is to promote awareness among the rural people to integrate the handicapped persons in easy works.

In Bangladesh, yet the major services for the mentally retarded persons center on special education and some vocational training. Little has been done about their integration. Practically nothing has been done for the rural mentally retarded persons. Yet all the NGOs together could not bring even 1% of the total mentally retarded population under any of their programs. And the remaining 99% of the Mentally Retarded persons of the country still remain deprived from the facilities of special education, training and other services.

Bangladesh Government, through the Social Welfare Department runs the National Center for Special Education (NCSE) at Mirpur in Dhaka. Here few children with mental retardation, hearing and visual impairments have facilities of special education and residential care. The center now introduced Special Teacher Training and Staff Training programs, too.

Yet there is no National Policy for the mentally retarded persons in Bangladesh. The NGOs and private bodies are practically doing some trials and errors with the mentally retarded persons and their families. However, due to some activities of different NGOs during last 30 years, some urban people and medical doctors have become aware of mental retardation to some extent. On the other hand, due to improved medical care and countrywide immunization programs now the mentally retarded persons are experiencing relatively longer life span. Previously, most of the severe and profound mentally retarded children were dying during infancy or babyhood due to wrong treatment, ignorance of the family members, lack of immunization and many other drawbacks. Now relatively more number of adult mentally retarded persons are seen in all places of the country, including rural areas.

The birth of a mentally retarded child in a family is a serious problem to the parents and other family members. The nature, number and seriousness of the problems are positively co-related with the degree of handicapped conditions of the child (Sufi, 1992).

The researcher associated herself with The SIVUS Institute in 1992 and served the Day Center as volunteer special education teacher and counselor until she joined Rajshahi University Psychology Department as a teacher. At present she is a member of the Governing Body of the SIVUS Institute and monitoring the activities of the volunteers who are visiting the houses of the mentally retarded children in an around Rajshahi city. The researcher is closely acquainted with about 100 mentally retarded persons of Rajshahi City since 1992. She studied them during her graduation course. When she visited them at their special school, she became attached to their special education, curriculum development, counseling and many family activities. On completion of her graduation, she continued to volunteer herself with the programs of the special education schools and day centers. She is invited to the family programs of many mentally retarded children and the relationship continued. When she first meet them in 1992, they were children or in their teen ages. Now they are grown-up adults. Some of them have got married and have children of their own.

Considering her personal observation since 1992 and the feedback she is receiving from her university students, she strongly feels that the magnitudes of the problems with the mentally retarded persons are increasing day by day in Bangladesh. Aging of the mentally retarded persons has significantly increased and the Government now must take some responsibilities. But unless there is a National Policy for the mentally retarded persons in the country it is really difficult to co-ordinate the activities of the government offices, non-government organizations, private bodies and the concerned families.

To facilitate the draft of a National Policy she has undertaken this research work entitled 'Psycho-social Correlates of Mental Retardation: A Study of Some Selected Cases'. The psycho-social correlates include health, education, employment, housing and social security of the mentally retarded persons in Bangladesh. But before entering into the depth of these aspects it is pertinent here to discuss the concept of mental retardation.



## **Mental Retardation:**

We do not find any nation that can claim it to be free from the problems of mental retardation. Of four billion inhabitants on our planet, about 1 to 3 percent are Mentally Retarded (WHO, 1968). Mental retardation is a serious social problem that is viewed from different social angles by people of different disciplines. The medical people consider mental retardation from the viewpoint of disease and treatment. Pedagogists consider the mentally retarded persons as slow learners. Psychologists view it as sub-normal intellectual capacity and psychosocial immaturity that lead to maladaptive behaviour. However, all of them are interested to understand the nature and causes of mental retardation from a scientific point of view.

## **Ancient and modern views about mental retardation:**

### **Ancient views:**

People were aware of the problem of mental retardation from ancient time and the ancient people also tried to understand and explain mental retardation with their limited knowledge. A brief review of the ancient views here may be interesting as well as enlightening with regard to some aspects of mental retardation.

Description of Mentally retarded children is found to a significant extent in Sanskrit literature. Terms such as *Jada*, *Buddhimandyam*, *Manasammandhyam*, *Mudha Budhi*, *Manasikadurblyam*, etc. are used to explain Mental Retardation (Kapila, 1964).

According to old Sanskrit texts, diseases and health are explained on the basis of *Tridosha*-the theory of three humours. Deficiency or excess in any one or all the three humours (supporting elements) of Personality (Prakriti) results in the discordance which is called *Roga* or disease. Similarly anything that afflicts the body or cell self (living personality) or both is called a disease. Mental Retardation, which is a deficiency (Mandata) in cognitive plane (Manasika), is therefore a disease according to the ancient Sanskrit literature. According to these literatures a *Jada* or Mentally Retarded child is born due to the Morbid humours that are provoked by the deficits of Spermoplasm (Vijatmkadosh), the condition of the Uterus (Ashaya), Season (Kala) and the defects of the Mother's diet and behaviour (Maturahara viharcdoshaith) during gestation. It was postulated that a child is born out of some of the following factors:

Buddha, Mohammed, 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 in infanticide and the establishment of foundling homes), many children were sold into slavery, abandoned, or left out in the cold. Toward 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 *tabula rasa*, a blank slate. This would profoundly influence the care and training provided to individuals with mental retardation. He also was the first to distinguish between mental retardation and mental illness; "Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all" (Doll, 1962).

In Greece and Rome, the retarded persons were viewed with horror and exposed so that he or she might perish. The word idiot comes from the Greek and it means a person who can not take part in public life and can not take part in conversation. The term imbecile had its origin in *Bacillum* meaning a short stick. An imbecile was a person who could not stand unsupported. Even today the words are used with contempt. In sparta all children at a state of their life were viewed by civic fathers and the handicapped children including the mentally retarded children were condemned to death. In ancient times even in India, an officer was appointed to single out the handicapped children and they were put to death. Marcus Valerius, a first century poet describing children with mental handicap writes *acute capit et auribus longibus, quae is moventur ut assellorum*, (with narrow heads and long ears which they move in the manner of asses). During the Roman Empire deformed idiots were kept in many household for amusements. Unfortunately even today persons with mental handicap often become sources of amusements for people.

The Jewish Talmud stresses that Mental Retardation is a mental disease, not connected in any way with diabolical possession and that the physicians, not the priest

should be consulted for their treatment. It classifies epileptics and retarded persons under the same headings. It also stated that persons suffering from Mental Illness were not held responsible for their actions and therefore should not be punished.

The Holy Quran however has showed a much more reasonable attitude. Quran says *Give not unto those who are weak of understanding the substance which Allah has appointed you to preserve for them but maintain them therewith and clothe them and speak kindly to them.* In the Holy Quran, there are descriptions of the mentally retarded persons in Sura Nesa, Sura Mariam and in many other places. These 'Aayats' clearly described the conditions and the responsibilities of the society towards the mentally retarded persons (Afsaruddin, 1988).

The great Protestant reformer Martin Luther maintained that idiots are illegitimate children of the devil and actually recommended that an imbecile boy of 12 be drowned. The word Cretin came from the word Chretien meaning Christian. This name has its origin in hatred to Christians at that time.

Today, the words *fool, imbecile, or idiot* are no longer in use; rather the term Mental Retardation is used to describe various forms of mental deficiency (Sufi, 1992).

The human settlement started in Bangladesh approximately 5000 years ago and the Mentally Retarded people were present from the very beginning. In the old Bengali literatures many references are found related to these dull people. The characters were shown sometimes as a laughing stock, sometimes as a helpless one. In many novels the characters were shown as a burden and source of anxiety to the family. In Bengali language they were termed as *Boka, Gadha, Adha Pagla*, etc (Sufi, 1992).

### **Modern scientific views:**

The terms Mental Retardation or Mental deficiency or Hypophrenia or Oligophrenia are often synonymously used and it is sometimes hard to define these separately.

The scientists concentrated their attention to the concept of mental retardation mainly during the decade of sixties. They understood that Mental Retardation refers to sub-

average general intellectual functioning which originates during the developmental period of a child and is associated with impairment in adaptive behaviour.

The sub average general intellectual functioning group includes all individuals whose performance on suitable objective tests of general intellectual ability is more than one standard deviation below the population mean. The upper limit of the developmental period is considered to be at approximately sixteen years.

Adaptive behaviour is manifested in three principal manners: (1) maturation, (2) learning, and (3) social adjustment. Each of these three factors assumes primary importance during a certain stage of developmental period. Thus maturation, which refers to the rate of development of the sensory motor skills such as seating, walking, talking, is the important criterion of adaptive behaviour during the pre-school years. Learning, which is defined as ability to acquire academic skills, is important during the school-age years. Social adjustment assumes primary importance at the adult level. The principal indicators of social adjustment at the adult level are:

The degree to which the individual is able to maintain himself independently in the community and in gainful employment as well as his ability to meet and to conform to other personal and social responsibilities and standards set by the community (Heber, 1959).

The quality of interpersonal relationship is an important manifestation of adaptive behaviour during the pre-school and school periods. However, social adjustment is considered the primary criterion of adaptive behaviour only at the adult level.

Kolb (1962), writing the preface to *Mental retardation* has the following pertinent comment to make.

"We are concerned here with a consideration of those conditions given innately through genetic determinants or as they occur in the early developmental process of the growing fetus or infant which lead to arrest or limitation of cerebral development so as to preclude the successful evolution of an intellectual capacity adequate for an independent social existence".

Such a broadly based statement will not only include conditions that produce chemical and anatomical disturbances of the nervous systems which limit the capacity

of the brain to respond to environmental stimuli and to integrate such stimuli, but also those conditions resulting from environmental deprivations that impair the full functioning of the otherwise well developed and intact central nervous system.

With the change of attitude towards the mentally retarded persons throughout the world, the definition of mental retardation also has changed a lot. We find the most recent definition, given in the 7th World Congress of the International Association for the Scientific Study on Mental Deficiency, as follows:

Mental Retardation is not a disease or single entity, rather a term applied to a condition of retarded mental development present at birth or in early childhood and is characterised mainly by limited intelligence combined with difficulty in adaptation. Hence mental retardation is impaired mental ability. A retarded child learns more slowly and at maturity his capacity to understand will be less than normal. He finds difficulty in learning, social adjustment and economic productivity (Sen and Dutta, 1985).

According to Lahey and Ciminero (1980) Mental Retardation is defined by three criteria in the official definition of the American Association on Mental Deficiency (AAMD, 1973).

AAMD has defined Mental Retardation referring: "Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period."

Individuals labeled as mentally retarded, therefore, will exhibit all three of the following characteristics:

Generalized deficiencies in intellectual functioning: The retarded individual is deficient in many aspects of intelligent behaviour. An individual with specific deficits, such as learning disabilities, would not be considered mentally retarded, even if the deficits were severe (Lahey and Ciminero, 1980).

Deficits in adaptive behaviour: In addition to low scores on an intelligence test, the retarded individual also shows serious deficits in adaptive behaviour. This term refers to deficits in a broad range of behaviours needed to adapt to the physical and social

demands of daily living, such as dressing and feeding oneself, using public transportation, as well as the presence of a broad range of maladaptive behaviours. A list of the general areas of adaptive and maladaptive functioning covered by the 'AAMD Adaptive Behaviour Scale' is given by Nihira, *et al.* (1974). That scale is the most widely used measure of adaptive functioning. While it is a standardized measure, it is somewhat subjective as it relies on estimates of the individual's functioning by parents, teachers and other characters instead of direct measures of behaviour.

Adaptive behavior has been an integral, although sometimes unstated, part of the long history of mental retardation and its definition. In the 19th century, mental retardation was recognized principally in terms of a number of factors that included awareness and understanding of surroundings, ability to engage in regular economic and social life, dependence on others, the ability to maintain one's basic health and safety, and individual responsibility (Brockley, 1999). Today, fulfillment of these personal and social responsibilities, as well as the performance of many other culturally typical behaviors and roles, constitutes adaptive behavior.

The 1961 manual (Heber, 1961) discussed adaptive behavior with respect to maturation, learning, and social adjustment. This framework, reiterated in 1983, described adaptive behavior limitations consisting of "significant limitations in an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social maturity that are expected for his or her age level and cultural group, as determined by clinical assessment and, usually, standardized scales" (Grossman, 1983).

The 1983 manual characterized the tasks or activities encompassed by adaptive behavior (and, plausibly social competence) as:

In infancy and early childhood: sensorimotor development, communication skills, self-help skills, socialization, and interaction with others;

In childhood and early adolescence: application of basic academic skills in daily life activities, application of appropriate reasoning and judgment in mastery of the

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environment, and social skills participation in group activities and interpersonal relations; and

In adolescence and adult life: Vocational and social responsibilities.

Adaptive behaviour measures while normed on representative, nation samples, which have extensive reliability and validity information are heavily dependent upon the informant's ability to give reliable and information. Several of the more widely used adaptive instruments include: *Vineland adaptive behavior scales*, (Sparrow, et al. 1984a, 1984b, 1985), *AAMR Adaptive Behavior Scales-Residential and Community*, (Nihira et al. 1993), *Comprehensive Test of Adaptive Behavior and Normative Adaptive Behavior Checklist* (Adams and Hartleben, 1984), *Scales of Independent Behavior*, (Bruininks et al. 1984), and *The Adaptive Behavior Inventory*, (Brown and Leigh, 1986). AAMR recommends that information about a student's adaptive behavior should come from a variety of sources and that strengths as well as weaknesses be considered when developing an intervention plan. In addition both in-school and out-of-school adaptive behavior should be addressed prior to making a determination of special education eligibility.

Onset during the developmental period: Virtually all mental retardation is first apparent in early childhood. The most severe cases are detectable in infancy and milder cases are identified in therapy school grades in most cases. Even when mental retardation is not identified until the school years, however, it almost always has existed prior to that time. In a few cases, the mental retardation is only used if the brain damage occurs during the "developmental period" (*i.e.*, before the age of 18). Otherwise the term organic brain disorder is applied (Lahey and Ciminero, 1980).

According to Carson *et al.* (1996) mental retardation is defined by the American Psychiatric Association (1994) in DSM-IV as "significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period that is accompanied by significant limitations in adaptive functioning" in certain skill areas such as self-care, work, health and safety.

To qualify for the diagnosis, these problems must have begun before the age of 18. Mental Retardation is thus defined in terms of behavioural performance. The definition says nothing about causal factors- which may be primarily biological, psychosocial, socio-cultural, or a combination of these. By definition, any functional equivalent of mental retardation that has its onset after age 17 must be considered a 'dementia' rather than 'mental retardation'. The distinction is an important one, because, the psychological situation of a person who acquires a pronounced impairment of intellectual functioning after attaining maturity is vastly different from that of a person whose intellectual resources were subnormal throughout all or most of his or her development.

According to Sheerenberger (1983), the elements of the definition of mental retardation were well accepted in the United States by 1900. These included: onset in childhood, significant intellectual or cognitive limitations, and an inability to adapt to the demands of everyday life. In 1910 an early classification scheme proposed by the American Association on Mental Deficiency referred to individuals with mental retardation as feeble-minded, meaning that their development was halted at an early age or was in some way inadequate making it difficult to keep pace with peers and manage their daily lives independently (Committee on Classification, 1910). Three levels of impairment were identified: *idiot*, individuals whose development is arrested at the level of a 2 year old; *imbecile*, individuals whose development is equivalent to that of a 2 to 7 year old at maturity; and *moron*, individuals whose mental development is equivalent to that of a 7 to 12 year old at maturity.

Over the next 30 years, the definitions of mental retardation focused on one of three aspects of development: the inability to learn to perform common acts, deficits or delays in social development/competence, or low IQ (Yepsen, 1941). An example of a definition based on social competence was proposed by Edgar Doll who proposed that mental retardation referred to "social incompetence, due to mental sub-normality, which has been developmentally arrested, which obtains at maturity, is of constitutional origin, and which is essentially incurable" (Doll, 1936). Fred Kuhlman, who was highly influential in the early development of intelligence tests in the United



States, believed mental retardation was "a mental condition resulting from a subnormal rate of development of some or all mental functions" (Kuhlman, 1941).

As a result of the conflicting views and definitions of mental retardation, a growing number of labels used to refer to individuals with mental retardation, and a change in emphasis from a genetic or constitutional focus to a desire for a function-based definition, the American Association on Mental Deficiency proposed and adopted a three part definition in 1959. "Mental retardation refers to sub-average general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior" (Heber, 1961).

The most recent change in the definition of mental retardation was adopted in 1992 by the American Association on 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 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" (American Association on Mental Retardation, 1992).

### **Levels of Mental Retardation:**

While the medical and psychosocial communities were developing an acceptable definition and classification system, the educational community adopted their own system of classification. Their three level system separated school age children with mental retardation into three groups based on predicted ability to learn (Kirk *et al.* 1955). Children who were *educable* could learn simple academic skills but not progress above fourth grade level. Children who were believed to be *trainable* could learn to care for their daily needs but very few academic skills. Children who appeared to be *untrainable* or totally dependent were considered in need of long term care, possibly in a residential setting. Some form of this scheme is still in use today in many school systems across the country.

DSM-IV attempts to blend the 1977 and 1992 definitions put forth by the American Association on Mental Retardation. It adopts the 1992 definition, but retains the severity level classification scheme from the 1977 definition. The upper IQ limit is 70, and an individual must have delays in at least two of the 10 areas outlined in the 1992 definition. In general, the overview of mental retardation in DSM-IV is thorough and easy to follow. However, it should be noted that comprehensive cognitive and adaptive skill assessment is necessary to make the diagnosis; it should not be made on the basis of an office visit or developmental screening.

ICD-10 is the tenth revision of the International Classification of Diseases (WHO, 1993). ICD-10 characterizes mental retardation as a condition resulting from a failure of the mind to develop completely. Unlike DSM-IV and the Classification Manual of the AAMR, ICD-10 suggests that cognitive, language, motor, social, and other adaptive behavior skills should all be used to determine the level of intellectual impairment. ICD-10 also supports the idea of dual diagnosis, suggesting that mental retardation may be accompanied by physical or other mental disorders (Biasini *et al.* 2000).

Different mentally retarded persons possess different levels of educational, social and work abilities. Four levels of mental retardation are recognized by DSM-IV, these are following:

**Mild mental retardation:** About 85 percent of all those who have IQ less than 70 are classified as having mild mental retardation. Their corresponding IQ range is 50-55 to approximately 70. Mild retardation is about eight times as frequent as all three more severe degrees of retardation combined. These children usually look normal, and show no signs of congenital malformations or physical handicaps. Such factors combine to make it unlikely that mild retardation will be recognised until after the child starts school and is identified as a slow learner. People in this group are considered as “educable” and their intellectual levels as adults are comparable with those of average 8 to 11 years. They can learn academic skills to approximately 6th grade level by late teens.

During age 0 to 5 years they can acquire, to a certain extent, social and communication skills, and they are rarely distinguished from the normal intelligent people until later age. Mildly retarded people are capable of social and vocational adequacy with proper education and training. As adults they are likely to be able to maintain themselves in unskilled jobs or in sheltered workshops. Further, they may marry and have children of their own. But they frequently need supervision and guidance under serious social or economic stress. The absence of brain pathology has led mild retardation being described in such terms as physiological, clinical, residual, primary, endogenous, and cultural-familial. With early diagnosis, parental assistance and special educational programmes, the large majority of mildly retarded individuals can adjust socially, master simple academic and occupational skills and become self-supporting citizens (Schalock *et al.* 1981).

**Moderate mental retardation:** About 10 percent of those with IQ less than 70 are classified as having moderate mental retardation. Their corresponding IQ range is 35-40 to 50-55. Brain damage and other pathologies are frequent. The moderately retarded may have physical defects and neurological dysfunctions that hinder fine motor skills, such as grasping and coloring within lines, and gross motor skills, such as running and climbing. During childhood these individuals are eligible for special classes. During 6 to 18 years they can learn functional academic skills to approximately 4<sup>th</sup> grade level by late teens if given special education. Moderately retarded individuals are likely to fall in the educational category of “trainable”, which

means that they are presumed able to master certain routine skills, such as cooking or minor janitorial work, if provide specialized instruction in these activities. In adult life, individuals classified as moderately retarded attain intellectual levels similar to that of average 7 year old child.

**Severe mental retardation:** Severely mental retarded are sometimes referred to as dependent retarded. Their corresponding IQ range is 20-25 to 35-40. They are corresponding to a maximum adult mental age of about 3 to 5 years. They commonly have congenital physical abnormalities and limited sensorimotor control. Genetic disorders and environmental insults, such as severe oxygen deprivation at birth, account for most of this degree of retardation. They can develop very limited skills for maintaining personal hygiene and self help. Throughout their whole lives they will be dependent on others for care. Of those with IQ less than 70, about 3 to 4 percent come under the category of severe mental retardation.

**Profound mental retardation:** The term life support retarded is sometimes used to refer to profoundly retarded individuals. Their corresponding IQ range is below 20-25. They are corresponding to an adult mental age no greater than that of the average 3 year old child. The profoundly retarded are totally dependent. They number only one in a thousand of the general population, and represent only 3% of all mentally retarded persons, but roughly 30% of the institutionalised retarded. During 0 to 5 years, they have gross retardation; minimal capacity for functioning in sensorimotor areas; and they need extensive nursing care. During age 6 to 18 years, some motor developments occur; they can not profit from training in self-help. Thus they remain totally incapable of self-maintenance and need complete care and supervision.

### **Clinical Types:**

Apart from the above mentioned categories of mental retardation in general, we find some specific clinical types of mental retardation. Each of these clinical types, discussed below, has its own distinctive symptomatic and etiological patterns.

### **Down's Syndrome:**

The term Down syndrome is taken from the name of the English physician, Dr. John Langdon Down, who is credited with first describing the condition in 1866 (Manfredini, 1988).

Langdon Down in 1866 first described this type of clinical condition associated with moderate and severe mental retardation. The term Mongolism is often used in referring to this syndrome. Afflicted persons frequently have almond shaped eyes (Golden and Davis, 1974).

People with Down syndrome are first and foremost human beings who have recognizable physical characteristics and limited intellectual endowment which are due to the presence of an extra chromosome 21 (Siegfried, 1990).

There are three main types of chromosome abnormalities in Down syndrome:

The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. This condition is called trisomy 21.

The second type is called translocation since the extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22. If translocation is found in a child with Down syndrome, it is important to examine the parents' chromosomes, since in at least one-third of the cases; a parent may be a carrier of the translocation. This form of chromosome error is found in 3-4 percent of the individuals with Down syndrome.

Another chromosome problem, called mosaicism, is noted in about 1 percent of individuals with Down syndrome. In this case, some cells have 47 chromosomes and others have 46 chromosomes. Mosaicism is thought to be the result of an error in cell division soon after conception (Siegfried, 1990).

Individuals with Down syndrome may vary significantly in terms of physical and psychological characteristics. The list of possible characteristics however should not obscure two important facts: clearly individuals with Down syndrome are first and foremost people who have similar needs, desires, and rights as others; and, the effects of intensive interventions with young Down syndrome children are only now being evaluated, hence making many of the historical descriptions of Down syndrome no longer accurate.

Some of the physical characteristics observed in persons with Down syndrome include the following: the back of the head is often flattened, the eyelids may be slightly slanted, small skin folds at the inner corners of the eyes may be present, the nasal bridge is slightly depressed, and the nose and ears are usually somewhat smaller. In the newborn there is often an excess of skin at the back of the neck. The hands and feet are small and the fingerprints are often different from chromosomally normal children.

Individuals with Down syndrome have loose ligaments and their muscle strength and tone are usually reduced. If the ligaments between the first two neck bones are loose, there may be a condition referred to as Atlanto-Axial Instability. About one-third of children with Down syndrome have congenital heart disease. Other congenital defects such as blockage in the bowels and cataracts, although rare, may also be present. Hearing deficits, visual problems, and thyroid dysfunction are often observed in persons with Down syndrome (Manfredini, 1988).

Researchers have established that the likelihood that a reproductive cell will contain an extra copy of chromosome 21 increases dramatically as woman ages. Therefore, an older mother is more likely than a younger mother to have a baby with Down syndrome. However, of the total population, older mothers have fewer babies; about

exceeds 17 inches, as compared with normal size of approximately 22 inches; Penrose (1963) also described microcephalic youngsters as being invariably short in stature but having relatively normal musculature and sex organs.

Microcephaly may result from a wide range of factors that impair the brain development, including intrauterine infections and pelvic irradiation of the mother during the early months of pregnancy (Koch, 1967).

Miller (1970) noted a number of microcephaly in Hiroshima and Nagasaki that apparently resulted from atomic bomb explosions during World War II.

The role of genetic factors is not as yet clear treatment is ineffective once faulty development has occurred, and, at present, preventive measures focus on the avoidance of infection and radiation during pregnancy.

"Hydrocephalus" is a relatively rare condition in which the accumulation of an abnormal amount of cerebrospinal Fluid (CSF) within the cranium causes damage to the brain tissues and enlargement of the cranium. In congenital cases of hydrocephalus, the head is either already enlarged at birth or begins to enlarge soon thereafter, presumably as a result of disturbance in the formation, absorption, or circulation of the cerebrospinal fluid (Wortis, 1973).

The disorder can also develop in infancy or early childhood following the development of a brain tumor, subdural haematoma, meningitis, or other such conditions. Hence the condition appears to result from a blockage of the cerebrospinal pathways and an accumulation of fluid in certain brain areas.

The clinical picture in hydrocephalus depends on the extent of neural damage. Which in turn, depends on the age of onset and the duration and severity of the disorder, while the expansion of the skull helps minimize destructive pressure on the brain, serious brain damage occurs nonetheless, leading to intellectual impairment varies, being severe or profound in advanced cases. A good deal of attention has been directed to the surgical treatment of hydrocephalus, and with early diagnosis and

treatment, this condition can usually be arrested before severe brain damage has occurred (Geisz and Steinhausen, 1974).

### **Cretinism:**

Cretinism provides a dramatic illustration of mental retardation resulting from endocrine imbalance. In this condition, the thyroid either has failed to develop properly or has undergone degeneration or injury; in either case, the infant suffers from a deficiency in thyroid secretion. Brain damage resulting from this insufficiency is most marked when the deficiency occurs during the prenatal and early postnatal periods of rapid growth.

In severe cases of cretinism the individual has a dwarf like thick body and short, stubby extremities. Height is usually just a little over 3 feet; the shortness is accentuated by slightly bent legs and a curvature of the spine. The individual walks with a shuffling gait that is easily recognizable and has a large head; thick eyelids give the person a sleepy appearance. Other pronounced physical symptoms include a broad, flat nose, large and floppy ears, a protruding abdomen, and failure to mature sexually. Most individuals with cretinism fall within the moderate and severe categories of mental retardation. Early treatment of cretinism with thyroid gland extract is considered essential; infants not treated until after the first year of life may have permanently impaired intelligence.

As a result of public health measures on both national and international levels with respect to the use of iodized salt and the early detection and correction of thyroid deficiency, severe cases of cretinism has become practically non-existent in the USA and in most of the developed countries. But such is not the case in other countries including Bangladesh.

### **Phenylketonuria (PKU):**

PKU, which stands for Phenylketonuria, is an inherited metabolic disease (also called an inborn error of metabolism) that leads to mental retardation and other developmental disabilities if untreated in infancy. With an inborn error of metabolism, the body is unable to produce proteins or enzymes needed to convert certain toxic



chemicals into nontoxic products, or to transport substances from one place to another (Glanze, 1996).

The body's inability to carry out these vital internal functions may result in neurological damage. In the case of PKU, the amino acid called phenylalanine accumulates. As phenylalanine builds up in the bloodstream, it causes brain damage. Infants with untreated PKU appear to develop typically for the first few months of life, but by twelve months of age most babies will have a significant developmental delay and will be diagnosed with mental retardation before school entry.

PKU is inherited as a single-gene disorder. Single-gene disorders are caused by a mutant or abnormal gene. They can be inherited in one of three patterns: autosomal dominant, autosomal recessive and X-linked. PKU is an autosomal recessive disorder. Each parent of a child with PKU carries one defective gene for the disorder and one normal gene. In a recessive condition, an individual must have two defective genes in order to have the disorder. Individuals with only one copy of a defective gene are called "carriers," show no symptoms of having the disease, and usually remain unaware of their status until they have an affected child. In order for a child to inherit PKU, both parents must be PKU carriers. When this occurs, there is a one in four chance of their producing an affected child with each pregnancy. Boys and girls are equally at risk of inheriting this disorder.

Although such symptoms as skin rashes (eczema), microcephaly, tremors, jerking movements of the arms or legs (spasticity), unusual hand posturing, seizures, hyperactivity, delayed mental and social skills, a distinctive "mousy" odor to the urine and sweat, light coloration (frequent finding of light complexion, blond hair, and blue eyes) may become apparent during the early weeks of life (Jonathan, 2002).

PKU occurring in about 1 in 20,000 births retarded individuals in institutions who suffer from PKU number about 1 in 100 (Holmes, 1972; Schild, 1972). Most of the older PKU patients show severe to profound Mental Retardation, with the median IQ of untreated adult phenylketonurics being about 20. Perry (1970) has reported the cases of two untreated PKU patients with superior intelligence. These findings have made PKU something of an enigma.

Before the 1960s, most infants born with PKU developed mental retardation and cerebral palsy. Although treatment for PKU using a low phenylalanine diet was first described in the 1950s, the inability to detect PKU early in the child's life limited effective treatment.

The first newborn screening test was developed by Dr. Robert Guthrie in 1959 specifically to test for PKU. This simple, yet very effective and economical test was developed to screen newborn infants for PKU before leaving the hospital. Today, all states routinely screen newborns for PKU. To test for PKU, the infant's heel is pricked and a few drops of blood are taken. This blood sample is then tested in a state laboratory for abnormal amounts of phenylalanine.

The normal phenylalanine level is less than 2 mg/dl. Those with phenylalanine levels of 20.0 milligrams per deciliter (mg/dl) or higher are considered likely to have "classical" PKU (Yannicelli *et al.* 1990). Infants with these high levels are further tested to confirm the diagnosis before treatment is started. Some infants will have more modest elevations of blood phenylalanine and are said to have "mild hyperphenylalanemia." Today many clinicians believe that any child with a phenylalanine level greater than 6 or 8 mg/dl should be treated with a modified phenylalanine restricted diet.

Experts recommend that testing for PKU should be done when the infant is at least twenty-four hours of age but less than seven days old. If an infant is tested too soon after birth, there is a chance that some cases of PKU will be missed as the phenylalanine level will not have risen yet. Now that many hospitals are discharging mothers and infants twenty-four hours after birth, there is a greater likelihood of this happening. The American Academy of Pediatrics recommends that infants receiving the test during the first twenty-four hours of life be re-tested at two to three weeks of age during their first postnatal pediatric visit (March of Dimes, 1994).

Although PKU is not preventable, its symptoms can often be treated successfully through the use of a carefully regimented diet. The diet consists of foods that have restricted phenylalanine content. Babies are given a special formula that contains very

low phenylalanine levels; then they gradually progress to eating certain vegetables and other foods that are low in phenylalanine. Affected children must have their blood tested regularly to ensure the presence of the correct level of phenylalanine. Foods recommended for those affected by PKU contain small amounts of protein, such as fruits and vegetables, limited amounts of cereal and grain products and special low protein products available through mail-order. High protein foods such as meat, fish, eggs, poultry, dairy products, nuts, peanut butter, legumes, soy products and products containing NutraSweet should be avoided (Yannicelli *et al.* 1990).

Therefore, women who have PKU should be on a phenylalanine restricted diet at least one year before pregnancy and should stay on the diet while breast-feeding to increase the chance of having a healthy child (Levy, 1988).

### **Cultural-familial Mental Retardation:**

Children who fall under this category are usually mildly retarded. They make up the majority of persons labeled as mentally retarded. These children show no identifiable brain pathology and are usually not diagnosed as mentally retarded until they enter school and have serious difficulties in their studies. A number of investigators have pointed out, however, most of these children come from poverty stricken, unstable, and often disrupted family backgrounds characterized by a lack of intellectual stimulation, an inferior quality of interaction with others, and general environmental deprivation (Birns and Bridger, 1977; Bragnisky and Bragnisky, 1974; Feurstein, 1977; Heber, 1970).

They are raised in homes with absent fathers and physically or emotionally unavailable mothers. During infancy they are not exposed to the same quality and quantity of tactile and kinaesthetic stimulation as are found in case of other children. Often they are left unattended in a crib or on the floor of the dwelling. Although there are noises, odors, and colors in the environment, the stimuli are not as organized as those found in the middle class and upper class environments. For example the number of words they hear is limited, with sentences brief and most commands carrying a negative connotation (Tarjan and Eisenberg, 1972).

### **Causes of Mental Retardation:**

Mental retardation is highly heterogeneous as to cause. More than 250 biologic causes are known, most of which can be grouped under the general categories of chromosomal abnormalities, other genetic factors, prenatal and perinatal factors (*e.g.* anoxia), acquired childhood disorders, environmental factors (*e.g.* lead) (Kaplan *et al.* 1994) and socio-cultural factors.

Knowing the cause in a particular case can sometimes provide important clues for understanding an individual's presentation; however, only approximately 25% of cases of mental retardation have a known biologic cause; in the remaining 75% of cases, the cause is unknown or is traceable to nonbiologic (*e.g.* psychosocial) factors (Van Silka and Hauser, 1997).

Scientists have found that Mental Retardation may be caused by various factors. These factors may broadly be classified into the following categories.

#### **Biological causes:**

**Genetic-Chromosomal Factors:** Mental retardation tends to run in families. This is particularly true of Mild retardation. However, poverty and socio-cultural deprivation also tend to run in families. So it is difficult to discern accurately the role exactly played by hereditary factors in causing such mild mental retardation.

Genetic and chromosomal factors play a much clearer role in the etiology of relatively rare types of mental retardation such as Down's Syndrome. Specific chromosomal defects are responsible for metabolic alterations that adversely affect development of the brain. Genetic defects leading to metabolic alterations may, of course, involve many other developmental anomalies besides mental retardation. In general, the mental retardation most often associated with known genetic- chromosomal defects is moderate to severe in degree.

Extraordinary technical developments in recent years have permitted an accurate and detailed study of the individual chromosomes of man. In 1956 it was demonstrated that a normal human being possesses 46 chromosomes. But individuals affected with Down's syndrome have 47 chromosomes, the extra member being one of the small chromosomes

of the G group. This trisomy condition is the consequence of meiotic nondisjunction, or failure of proper separation of a pair of homologous chromosomes during the maturation divisions of the egg. Down's syndrome appears with increasingly higher frequencies among children of mothers of advancing age; the oocyte of older women is apparently prone to the abnormal process of nondisjunction. In rare instances, Down's syndrome is not caused by non disjunction, but by another chromosomal aberration, translocation.

Researchers have long believed that the 'extra' chromosome in Down's Syndrome is in some way contributed by the mother. But in 1973 it was learned that in certain instances it is in fact contributed by the father (Sasaki and Hara, 1973; Uchida, 1973).

It has been known for many years that the incidence of Down's Syndrome increases in regular fashion with the age of the mother. A woman in her 20s has about 1 chance in 2000 of having a Down's Syndrome baby, whereas the risk for a woman in her 40s is 1 in 50 (Holvey and Talbot, 1972). Evidence of this type led normally to the speculation that the capacity of the older woman to produce a chromosomally normal fetus was somehow impaired by the aging process.

Quite recent research, however, strongly suggests that age of the fathers at conception is also implicated, particularly at the higher ranges of parental age (Stene, 1977). In one study involving 1,279 cases of Down's Syndrome in Japan, Matsunaga *et al.* (1978) demonstrated an overall increase in incidence of the syndrome with advancing paternal age when maternal age was controlled. The risk for the fathers aged 55 years and over was more than twice that for fathers in their early 20s. Thus it seems that advancing age in either parent increases the risk of the Trisomy 21 anomaly. As yet we do not understand how aging produces this effect; a reasonable guess is that aging is related to cumulative exposure to varied environmental hazards, such as radiation, that might have adverse effects on the process involved in zygote formation or development.

But whatever the cause of the chromosomal anomaly, the end result is the distortion in the growth process characteristic of this clinical syndrome. There is no known effective treatment. When parents have had a child with Down's Syndrome, they are usually quite concerned about having further children. In such cases genetic counseling may provide

some indication of the risk of abnormality. In recent years, the technique known as 'amniocentesis' has made it possible to diagnose most cases of Down's Syndrome 'in utero', thus permitting parents to make a rational choice concerning termination of pregnancy if the fetus is abnormal.

**Deletion:** sometimes a piece of chromosome breaks off, resulting in a deletion of genetic materials. The effects of the loss of a portion of chromosome depend on the particular genes lost. A large deletion, with the loss of many genes, is incompatible with life.

Dr. Jerme Lejeue and his colleagues at the University of Paris described in 1963 the peculiar effects in an infant of the loss of a portion of the number 5 chromosome of group B. Affected infants have a rounded, moonlike face and utter feeble, plaintive cries described as similar to the mewling of a cat. In fact, the disorder has been named the *cri du chat* or 'cat cry' syndrome. Such unfortunate infants are mentally and physically retarded. Although originally thought to be exceedingly rare, at least 70 cases of this disorder have been reported since the initial discovery (Volpe, 1975).

The 'cri du chat' syndrome, are traceable to a loss, or deletion, of a portion of a chromosome. A type of cancer (chronic myeloid leukemia) has been associated with a specific aberrant chromosome (Philadelphia chromosome). A large proportion, as many as 25 percent, of early aborted human fetuses has been found to possess abnormal chromosome complements (Volpe, 1980).

**Infections and toxic agents:** Mental Retardation may be associated with a wide range of conditions due to infection. If a pregnant woman has syphilis or is afflicted with German Measles, her child may suffer brain damage. Brain damage may also result from infections occurring after birth, such as viral encephalitis.

A number of toxic agents, such as carbon monoxide and lead, may cause brain damage during fetal development or after birth. Immunological agents, such as antitetanus serum or typhoid vaccine, taken by mother, may lead to brain damage of the fetus. Similarly, certain drugs taken by the mother during pregnancy may lead to congenital malformations; an overdose of drugs administered to the infant may result in toxicity and brain damage. In rare cases, brain damage results from incompatibility in blood types

between mother and fetus-conditions known as Rh, or ABO, system incompatibility. Fortunately, early diagnosis and blood transfusions can now minimize the effects of such incompatibility.

**Prematurity and trauma:** Follow-up studies of children born prematurely and weighing less than about 5 pounds at birth have revealed a high incidence of neurological disorders and often mental retardation. In fact, very small premature babies are many times more likely to be mentally retarded than normal infants (MacDonald, 1964; Rothschild, 1967). Physical injury at birth can also result in retardation. Isaacson (1970) has estimated that in 1 birth out of 1000 there is brain damage that will prevent the child from reaching the intelligence level of a 12-year-old. Although normally the fetus is well protected by its fluid-filled bag during gestation and its skull appears designed to resist delivery stressors, accidents do happen during delivery as well as after birth. Difficulties in labour due to malposition of the fetus or other complications may irreparably damage the infant's brain. Bleeding within the brain is probably the most common results of such birth trauma. Use of forceps during delivery may cause brain damage that may lead to mental retardation.

Anoxia or lack of sufficient oxygen to the brain stemming from delayed breathing or other causes-is another type of birth trauma that may damage the brain. Anoxia may also occur after birth as a result of cardiac arrest associated with operations, heart attacks, near drowning, or severe electric shocks.

**Ionizing radiation:** In recent years a good deal of scientific attention has been focused on the damaging effects of ionizing radiation on sex cells and other bodily 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. Sources of harmful radiation were once limited primarily to high energy X-rays used for diagnosis and therapy, but the list has grown to include leakage at nuclear power plants and nuclear weapons testing, among others.

**Malnutrition and other biological factors:** Deficiencies in protein and other essential nutrients during early development can result in irreversible physical and mental damage. Protein deficiencies in the mother's diet during pregnancy, as well as in the baby's diet after birth, have been pinpointed as particularly potent causes of lowered intelligence.

A limited number of cases of mental retardation are also associated with other biological agents, such as brain tumours that either damage the brain tissue directly or lead to increased cranial pressure and concomitant brain damage. In some instances of mental retardation-particularly of the severe and profound types-the causes are uncertain or unknown, although extensive brain pathology is evident.

### **Unknown Prenatal Influence:**

**Cerebral Malformations:** Anencephaly and hemi anencephaly are among the most common congenital brain malformations, invariably resulting in death at birth or shortly thereafter due to absence of one or both cerebral hemispheres or even greater portions of the central nervous system. Malformations of gyri include argyria, macrogyria and microgyria. The latter is a relatively common pathological condition found in the severely mentally retarded. Congenital porencephaly is characterised by large funnel-shaped cavities occurring anywhere in the cerebral hemispheres.

**Craniofacial anomalies:** Primary microcephaly is transmitted by a single pair of autosomal-recessive genes and invariably associated with moderate to severe retardation. Microcephaly may also be secondary to exogenous lesions, resulting from infections, trauma, or asphyxia. This term is reserved for adults with a head circumference of 17 inches or less; or children with a head circumference of less than 13 inches at 6 months, 14 inches at 1 year, or 15 inches at 2 years.

According to the Psychiatrists, Severe and Profound Retardation are associated with brain disease and often with congenital malformation and physical handicaps. The more severe the retardation, the more obvious it will be to non-professional observers and greater the probability of associated physical disabilities. Hence medical advice is likely to be sought earlier than in the case of mild retardation. Such disorders as Down's



syndrome, microcephaly and hydrocephaly may be easy to identify early, but it is extremely important to recognise disorders that may not be so grossly obvious but are treatable, such as cretinism, phenylketonuria, galactosaemia and hypoglycemia, in order to obtain the best possible results. Prompt recognition and appropriate intervention are important conditions for better adjustment and rehabilitation of mentally retarded persons.

### **Socio-cultural causes:**

It was formerly believed that all mental retardation was the result of faulty genes or of other causes of brain pathology. In recent years, however it has become apparent that adverse socio-cultural conditions, particularly those involving a deprivation of normal stimulation, may play a primary role in the etiology of mental retardation.

Two subtypes of mental retardation fall in this general category: (a) mental retardation associated with extreme sensory and social deprivation, such as prolonged isolation during the developmental years, as may have happened in the case of the wild boy of Aveyron and (b) cultural-familial retardation, in which the child is not subjected to extreme isolation but rather suffers from an inferior quality of interaction with the cultural environment and with other people. Since such socio-cultural impoverishment may be associated with genetic deficiency in some cases, the child born to a family in such circumstances may be doubly jeopardized. In any event, it has proven all but impossible to assess adequately the differential influences of nature and nurture in these cases. The field is rife with controversy and, regrettably, has involved one publicized case in which a researcher allegedly manipulated his statistics to prove that mental retardation is hereditary (Dorfman, 1978).

The developmental level of a growing individual depends on the integrity of the CNS and on environmental and psychological factors. The importance of environmental stimulation for child development has been appreciated since research on children in institutions showed that development was severely affected in a depriving environment, even if adequate physical care was provided. Poverty predisposes the child to many developmental risks, such as teenage pregnancies, malnutrition, abuse, poor medical care, and deprivation (Sebastian, 2002).

Islam *et al.* (1993) evaluated the socioeconomic status and the prevalence of mental retardation in Bangladesh. Results of a population-based study of the prevalence of mental retardation among 2 to 9 year old children in Bangladesh were reported. More than 10,000 children were screened for mental retardation and other disabilities. All children with positive screening results plus a random sample with negative results were referred for clinical evaluations. The prevalence rates per 1,000 of severe and mild mental retardation in this population were 5.9 and 14.4, respectively. As found in studies in developed countries, the prevalence of mild mental retardation was strongly and significantly associated with low socioeconomic status, whereas the association for severe mental retardation was relatively weak and not significant.

### **Mental Retardation in Bangladesh:**

No nation can claim to be free from the problem of mental retardation. In Sweden, 0.45% of the total populations are mentally retarded. In India, it is estimated that the number of mentally retarded persons could be anywhere between 18 and 20 million, to which about 0.4 million are being added every year (Sufi *et al.* 1996).

Population of Bangladesh was estimated 129.25 million (Banglapedia: National Encyclopedia of Bangladesh, 2003). There is no census report about the total number of mentally retarded persons in Bangladesh. It is very difficult to have an exact estimate of the mentally retarded persons in Bangladesh. Considering the similarities of the culture, economy and health conditions of Bangladesh with the Indians, WHO's report, etc. it is assumed that at least 3 % people are mentally retarded in Bangladesh (Sufi *et al.* 1996).

The urban population of Bangladesh is approximately 13% and roughly 400,000 mentally retarded persons live in the urban areas of the country. From the psychological point of view, the mentally retarded persons of upper and middle class families of the urban areas live in unfavourable conditions than the rural mentally retarded persons. As there are restrictions in their movements and social contacts, they remain confined inside their own houses. Those who attend special education classes can come out of their residence only during school hours and get little opportunity to make social contact with other persons. The lives of the adult female mentally retarded persons in the urban areas are far more miserable (Sufi *et al.* 1997).

There is a general tendency to hide their mentally retarded children from others in the higher socio- economic group. They usually try to appoint nurses or servants to attend their mentally retarded child. These mentally retarded persons in the towns get the least opportunity for social and interpersonal interactions (Sufi *et al.* 1996).

The middle class people also possess similar attitudes towards their mentally retarded children like the upper class socio- economic groups. The mild mentally retarded children are sent to the normal schools at the beginning. Most of the cases ultimately become school dropouts.

The mentally retarded children of the lower socio-economic groups enjoy more freedom in loitering in their own neighbourhood during day hours (Sufi *et al.* 1996).

Many mentally retarded children of the urban slums beg in the roads, loiter aimlessly or work casually as a day labourer. Many of these children may become involved with delinquency.

Rural mentally retarded persons get enough opportunity of free movements. Since the risk of road accidents are lesser in rural areas the mentally retarded children of both sexes get enough opportunities of loitering in the agricultural fields and the village markets. They get opportunity of being day labourers in the agricultural works and in cattle mending. The female mentally retarded persons get many job opportunities for household activities. In the villages, if the degree of retardation is of mild nature and the person is male, he gets an opportunity to look after the parental properties, business, household matters, etc.

At present there is no special education school in the rural areas. If the mentally retarded child is capable of speaking and hearing they usually attend the beginning classes of the normal schools, but ultimately they drop out of the school. If they become adult they get married in many cases. Arrangement of such marriage is not a serious problem. In the long run they become absorbed in household works. But for the mentally retarded females, the marriage may not last long. On separation from their husbands these female retarded persons come back to their parental houses.

In the rural areas, most of the profoundly retarded children die in their infancy period, owing to diseases, faulty handling, wrong diagnosis, ignorance, etc. Those who survive infancy period also die in their childhood age after a lot of sufferings. In the rural areas, only the mild and some of the moderately retarded persons can expect a longer life span, provided they learn to communicate and acquire some basic skills. Fortunately in the rural areas the mental retardates get relatively better scope for socialization and enjoy more social acceptance in comparison with urban mental retardates.

The life and daily routine works of the villagers differ from that of the people of the town. Marked differences are also seen among the different classes of population. Life

style of the rich people differs widely from that of the poor. The slum dwellers live differently from other sections of people. These differences in the living conditions determine the outlook and attitude of the different section of population towards mental retardation. These things must be kept in view while devising any programme to uplift and rehabilitate mental retardates in Bangladesh.

Marriage of the mentally retarded children is less common among educated group and apparently high among illiterate families. The frequency of marriage is higher among the rural people. Parents usually give a good portion of parental assets to their mentally retarded children. There are many evidences that the parents, usually of the mentally retarded females, offer dowry to the persons who marry their children. Such offers work as a good incentive to the poor persons to marry the rich mentally retarded females.

In Bangladesh, the mentally retarded persons live with their families. There is no residential Institution, like the Institutions found in Europe and many other neighbouring countries. They live with their parents when the parents are alive and with some other relation after the death of the parents.

The mental retardates of the low economic group both in rural and urban areas mostly live in the streets or other people's houses, and for their livelihood they mostly depend on the mercy of others.

Although Bangladesh is mainly a Muslim country, people of various cast and creed live in this country. The family laws are different for the Muslims and Hindus in the court of justice. The laws are quite old and these were introduced during British rule of India.

Muslim laws preserve equal rights of the mentally retarded persons on the parental property. But there are many drawbacks in the laws that finally fail to protect underhand transfers of the properties of the mentally retarded persons.

The culture and customs under Muslim laws and conventions emphasise provision for food and shelter for the mentally retarded persons and the responsibility for care taking is laid on the shoulders of the elder brothers or sisters or other near relatives in the absence of the parents.

Hindu law does not recognise any right of the mentally retarded persons on the parental properties. Under this law only those can inherit the parental properties who are allowed by religious rules to put fire on the dead body of the father. Usually profound or severely retarded Hindu people are not allowed by rule to put fire on dead father and thus he or she is deprived of the parental properties. After the death of the parents, they live on the mercy of their siblings. In India, the Hindu Disposition of property Act 1954 was amended which now reserves equal rights of the mentally retarded persons like their other siblings. The same act in Bangladesh was not amended and therefore, the Hindu mental retardates are still deprived of their parental property in Bangladesh.

The special education classes and day care centres available in Bangladesh do not differentiate the caste or class and the mentally retarded persons of all caste receive equal rights in the schools here (Roy, 1987).

There is no special law for the mental retardates of the Christians, the Buddhists and the Tribal people. The matters related to the rights and privileges of the Christians and Buddhists mentally retarded persons in the court of law are sometimes reported to be dealt with lunatic act. The Lunatic Act introduced by the British Government in India is still in existence in this country. This law has some clauses which are creating confusions between Mental Illness and Mental Retardation. And misuse of this law allowed interested parties to deprive many mentally retarded persons from their rights on properties.

However, in this country the mentally retarded persons are voters, tax payers and possess other rights equally as citizen of this country. But they are not provided with any special quotas for entering into job situations or other competitive situations.

The parents try to provide some treatment for their retarded children at the beginning but after some time they give up all attempts. Religious healing, ayurvedic and homeopathic treatments are very common practices both in the rural and urban areas. In the urban areas the parents try some psychiatric treatments if they get opportunity in the hospitals. Parents are not aware of either the importance or the existence of special education and

training programmes for the mentally retarded children. Their faulty attitude and misconceptions about mental retardation further worsens the situation.

### Medical Services in Bangladesh:

As mental retardation is primarily considered as a medical problem, it is pertinent here to make a short reference to the medical services now available in Bangladesh.

According to the WHO's declaration complete physical, social and mental well being is the healthy condition of a person. But in Bangladesh, the term "health" means only the physical health. The public health services are under the control of the Directorate of Health, headed by a senior physician of the country. There is one Ministry of Health and Population Control headed by a Minister. The Ministry declares Policy programmes and allocates funds for the programmes. The present health policy does not segregate the mental retardates from other types of patients. At a public health centre, the mentally retarded persons enjoy equal rights with all other patients.

In Bangladesh, big public hospitals are attached with all the seven medical colleges and IPGMR. There are Government hospitals with necessary facilities at all the district head quarters. At Upa Zilla level Government Health Complexes provide people with free medical services. Besides these Government programmes, there are many hospitals and health care centres throughout the country run by Christian Missionary Groups and NGOs. Treatment is cheap in most of these centres. There are also many private clinics where treatment is expensive.

Other than diagnosis and treatment the Health directorate undertake immunization programmes. Similar programmes have been undertaken by NGOs, having a nation-wide network, are rendering valuable services.

There are also some qualified Psychiatrists who also carry on treatment of the mentally retarded persons mostly by using some psychotic drugs. But unfortunately many of these mentally retarded persons develop drug dependence as a consequence of their treatment. Now a days, of course, the psychiatrists have become aware of this problem and they are now referring the clients to special schools and centres for the mentally retarded children.

Presently there are rural physicians (Palli Chikitschok) in most villages who are recognised by the Health Directorate to practice. They are required to complete a short course in medical science and are popularly known as National Doctors.

Besides the scientific Allopathic treatment, Homeopathy and Ayurvedic treatments are widely practised in the country. There are Homoeopathic and Ayurvedic physicians in many of the villages. Since they are readily available persons, the rural people usually consult them at first during any illness. When the illness takes a serious turn, or involves surgical operation, only then the villagers approach allopathic doctors.

From the above discussion it becomes apparent that scientific medical service, though increased at present, is far from being satisfactory to meet the need of millions of people. Apart from this, the beliefs and attitude of the people also complicate the situation.

In the early ages, the faith healers were the leading personalities to explain the conditions of the mental retardation. They interpreted the symptoms differently according to their own education and training.

Treatments with Ayurvedic medicines are also popular in Bangladesh. This treatment pattern was also invented in this sub- continent thousand of years ago. Ayurvedic medical books interpreted mental retardation in their own ways. Homeopathic medicines are widely practiced in this country, too. Unfortunately large majority of the Homeopathic physicians have no formal education from any Homeopathic Medical College. Whether the treatment is ayurvedic, homeopathic or allopathic the mentally retarded persons of this country are subjects of experiments. The physicians are engaged in Trials and Errors with them in the absence of effective health policy of the government. The ultimate result is drug dependency of the mentally retarded children, which is continued throughout their life.

There are differences in the treatment patterns of the mentally retarded persons between urban and rural areas, rich and poor families, educated and illiterate families, etc.

A large number of mentally retarded persons develop drug dependency due to faulty treatments and ignorance of the concerned medical practitioners. Ignorance of the



guardians jeopardizes the condition a little more. It could be avoided if the mentally retarded conditions could be detected in the early ages of the subjects.

Most of the parents of the mentally retarded persons in Bangladesh are not aware about their ward's real condition. Even they do not know the causes and symptoms of mental retardation. Majority of the parents and guardians of the mentally retarded persons in this country treat their wards as mentally ill. They usually seek help of every type of medical practitioners for their mentally retarded wards. They actually do trials and errors with their wards.

Following are the synopsis of common treatment patterns for the mentally retarded persons in Bangladesh.

Homeopathic and Ayurvedic treatments are widely practiced both in the rural and urban areas of Bangladesh. There are many Homeopathic and Ayurvedic physicians in the villages. Since they are the readily available persons, the people usually consult them at first during any illness. When the illness takes a serious turn or involves surgical operation, only then the villagers approach educated allopathic doctors in the nearby urban areas.

Homeopathic treatment is relatively popular among the rural people because of the lower cost and easy availability. It is sometimes the only treatment for all diseases to the poor people. Homeopaths both educated and uneducated, practice treatment of the mentally retarded persons since hundreds of years. To most of the Homeopaths, Mentally retarded persons are mentally weak persons. They use a number of Homeopathic medicines mainly for improving the memory and thought process.

Ayurvedic treatments are very old in this sub-continent. The main philosophy is to obtain medicine from the plants and minerals. Thousands of Ayurvedic medicines are available in the village market and people indiscriminately use these medicines, even without any formal prescription from an expert, for improvement of their mental capacity. Faith healing and miracle cures are also widely practiced in the rural areas of Bangladesh (Sufi *et al.* 1996).

The medical books available in the above mentioned treatment patterns rarely follow the classification systems of ICD- 10 (the tenth version of International Classification of Diseases) prepared by the World Health Organization or DSM-IV (the fourth edition of Diagnostic and Statistical Manual). These books also defined mental retardation ignoring the ICD-10 or DSM-IV classification. The medicines prescribed by the traditional medical practitioners for the mentally retarded persons are jeopardizing the situation.

**Allopathic Medication:** Most of the parents of the mentally retarded persons seek help from the general medical practitioners or psychiatrists for their wards. The general medical practitioners and the psychiatrists usually prescribe psychotropic medicines for the mentally retarded persons. The psychotropic drugs are more popular in the urban areas than in the rural areas.

An allopathic drug is a chemical compound that can affect the body's functioning. Psychotropic drugs are those chemical agents that have an effect on the mind. Psychotherapeutic drugs comprise the relatively small subsets that have established indications in the treatment of mental disorders.

Bangladesh's population was estimated 129.25 million (Banglapedia: National Encyclopedia of Bangladesh, 2003). It is assumed that about three percent of the population is mentally retarded. Providing medical care is the constitutional obligation of the government. The constitution mandates that: "it shall be a fundamental responsibility of the state to attain, through planned economic growth, a constant increase of productive forces and a steady improvement in the material and cultural standard of living of the people, with a view to securing to its citizens the provision of the basic necessities of life, including food, clothing, shelter, education and medical care" (Government of Bangladesh, 2002).

In response to the changing health situation of the country, reforms in the health sector particularly in the areas of management structure, service delivery mechanisms and utilization of both public and private sector resources are called for urgently.

Major efforts will be required for health protection through appropriate legislation and effective enforcement.

The Government of Bangladesh is committed to achieve the overall objectives of the “World Summit for Children” and the “ Programme of Action of the International Conference on Population and Development (ICPD)” held in Cairo in 1994. Thus, the health and population sector vision will be to provide adequate basic health care for the people of Bangladesh and to slow down population growth and to be responsive to clients’ needs, especially those of children, women and the poor (Government of Bangladesh , 2002).

A dismal scenario can be observed in the health sector where both primary and specialized health care services are still inadequate. Here, a serious demand for services exist for doctors, nurses, medicine, hospital care and so on. At present, doctor-population ratio is 1: 5506; hospital bed- population ratio is 1:3231 and per capita health expenditure is Tk. 135 per annum (Government of Bangladesh, 2002).

Again, malnutrition is wide spread in Bangladesh. About 76 percent of all households are deficient in calorie intake. Women and children are particularly affected by this chronic problem. Malnutrition in its severe form causes stunting and wasting in children and reduces capacity and productivity in adults. The malnutrition situation is very serious among pregnant women, which contributes to low birth weight, malnutrition and severe iodine deficiency in a large number of new-born babies.

### **Trend in the development of Health facilities:**

Infant mortality declined from 140 per 1000 live births in 1975 to 78 per thousand in 1996; maternal mortality from 6.2 in 1982 to 4.4 per 1000 live births in 1996; and Life expectancy rose from 45 in 1970 to 58 in 1996. There have been some outstanding achievements in the area of primary health care and sanitation. Expanded Programme of Immunization (EPI), leading to speedy expansion of immunization increased in coverage from 2 percent in 1985 to 77 percent in 1996. Dramatic improvement of the use of oral dehydration therapy has improved child survival significantly.

Over 96.7 percent of the people in the rural areas now use safe drinking water compared to 56 percent only in 1975. There has also been dramatic improvement in the coverage of the sanitary methods from 36.90 percent in 1996 to 54.1 percent in 2000 (Bangladesh Demographic and Health Survey, 2001). The trend of ratio of population to physicians and hospitals and hospital beds, although improving is still low. Availability of nurses is even worse. There is a strong need to improve availability of physicians, hospital beds and nurses, in addition to quality of medical services. There were very few health facilities and health professionals in the country.

The medical facilities in Bangladesh are being increased gradually which is evident from the table given below.

Year	Hospital		Govt. Dispensaries	Beds in		Registered doctors	Registered Nurses	Registered midwives
	Govt.	Private		Govt. Hospital	Private Hospital			
1984	568	164	1559	21870	4771	13500	580	3850
1985	596	164	1275	22874	4771	14591	6418	4399
1986	600	164	1275	23306	4771	16090	6912	5199
1987	608	267	1310	26575	6463	16929	7000	5837
1988	608	267	1310	26871	6463	18030	7390	6556
1989	608	267	1310	26913	n. a.	18917	8056	7035
1990	608	267	1310	n. a.	n. a.	20006	9274	7485
1991	610	280	1318	27111	7242	21004	9655	7713
1992	611	280	1362	27111	7242	21749	10607	9363
1993	611	292	1397	27637	7643	22400	9455	10104
1994	639	280	1397	28553	2747	24911	9630	7713
1995	645	288	1397	29106	8025	26482	13830	1110
1996	645	288	1362	29502	8025	27425	13830	11200
1997	650	288	1397	30081	8025	27546	15408	13211
1998	647	626	1397	30506	11371	28312	16972	14915
1999	663	626	1397	31722	11371	30864	17446	15235
2001	n. a.	n. a.	n. a.	43,443		32,498	18,135	15,794

Source: BBS, 2000  
UMIS, 2003

Even when the medical facilities are being gradually increased, a large portion of the population does not get proper medical care. Yet there are many villages where medical services have not yet reached and immunisation is yet unknown.

Over the 33 years of independence, the health situation of the population has improved quite remarkably. Small pox, malaria and cholera have been eradicated or

are no longer major killers. Life expectancy at birth reached 61.8 years in 2000. Total fertility rate was reduced from 3.4 in 1995 to 2.5 in 2000. The crude death rate dropped from 9.0 in 1995 to 3.7 in 2000 and is expected to decline further. Infant mortality rate declined to around 51.0 per 1000 live births in 2000 (BBS, 2001). Similarly, the under-5 mortality dropped from over 133 in 1995 to 82.4 per 1000 live births in 1998 (Ministry of Health and Family Welfare, 2001). In terms of physical facilities, there were 897 hospitals (610 in the public sector and 287 in the private sector) of different categories with 34,786 beds (27544 in the public sector and 7242 in the private sector) with one bed for every 3450 persons in the country in 1995. With regard to health and medical professionals, the country so far produced 32,498 graduate doctors by 2001 giving a doctor population ratio of 1:3.977. The doctor-nurse ratio was 2:1 (UMIS, 2003).

Despite these positive changes over the last 33 years, much remains to be done in the health sector. Even after considerable decline in the infant mortality rate and maternal mortality rate, they continue to be unacceptably high compared even to other developing countries. The quality of life of the general population is still very low. Low calorie intake continues to result in malnutrition in a large proportion of the population, particularly women and children. Diarrhea diseases continue to be a major killer and the number one cause of morbidity. Communicable and poverty-related diseases, that are preventable, still dominate the top 10 causes of morbidity and over sixty-five percent of all morbidity cases in 1996 were caused by communicable and poverty-related diseases (Government of Bangladesh, 2002).

The above mentioned paragraphs are the reports published by the Government of Bangladesh. From these reports it is understood that the health care facilities are yet inadequate in the country. The figures shown about the medical doctors are total figures of the country. The graduate medical doctors are living mainly in the urban areas. In rural areas the modern medical facilities are yet very poor or nil. Whereas nearly 80% of Bangladeshi people live in the rural areas and they are deprived of modern medical facilities.

The major causes of mental retardation in Bangladesh are ill healths of the mothers, defective births in the absence of qualified professionals, indiscriminate use of medicines, severe illness and diseases of the infants, faulty treatments, etc.

The Government reports mentioned in the above paragraphs clearly indicates that though the facilities increased, it did not increase proportionally with the increase of population.

## Review of Literature

**Theories and philosophies:** Different philosophies, methods and techniques are used in different countries for rendering services to the mentally retarded persons. Following discussion highlights three important approaches now adopted to deal with this problem of mental retardation.

**SIVUS Group Dynamic Principles:** SIVUS is an abbreviation of Swedish term "Social Individ Via Utveckling i Samvarkan" which means Socio Individual Development Through Co-operation. The SIVUS is based on group-dynamic principles, on knowledge of how all human beings develop both as individuals and at the same time as social beings. They are developing through their own propelling forces/ activities in order (in the frame of) to achieve a certain goal, to find a certain means that can satisfy their own needs, both materially and culturally. The process of these activities is: from their own needs, desires and interests; through their own efforts, activities or work; to their own experiences, ideas, theories, knowledge, results and development (Walujo, 1987).

It means the process is from practice, to theory and from theory again back to the new practice. This process of applying the achieved theory leads to achieving a better result and development in providing for his needs to survive and to live better and better.

The goal of the SIVUS project is supporting mentally retarded persons to function as independently as possible, both individually and socially, by considering individual ability, both within the area of provision and services for the mentally retarded and in the society in co-operation with others.

The work method used in SIVUS is characterized by actively taking part in co-operation with others, organized in small groups having fixed members, supervisors; and principal activity coming from the group member's mutual interests, functioning as democratically as possible, with other words through a social integration to achieve normalization (Sufi, 1993).

The "SIVUS Scale" used in evaluating the development of both individual member and the group as an unit was developed and standardized by Dr. Sophian Walujo and his associates in Sweden during 1974 and 1978. Sweden is the pioneer country to introduce and practice the theory in all aspects to uplift the mentally retarded persons. Until 1978, the programme was administered at NGO levels. Since 1978 up to now, SIVUS is a Swedish National programme under the control of The Swedish National Board of Health and Welfare. Presently, SIVUS is in practical application in at least 30 countries of the world and its output was proved as the most significant one among all the theories (Sufi and Yamashita, 1996).

**Portage Programme:** This is the home based programme where parents teach mentally retarded children according to structured, step-by-step package (Hoel *et al.* 1988).

Generally the service involves a home teacher visiting an individual family at regular intervals, assessing the child periodically and deciding with the parent on developmentally appropriate activities for the parent to carry out with the child. The Portage system (which originated in Wisconsin, USA, but which has been adopted internationally) the home teacher has a resource of activity cards linked to a developmental checklist. The teacher uses the cards to devise up to three or four instruction and recording sheets for the parent to follow and fill in during the week before the next visit (Shearer and Shearer, 1976).

There are some standard packages developed in English language. In many countries the Portage programme is adopted in their own languages. In Bangladesh, Dr. Sultana Zaman and her associates of the Protibandhi Foundation have developed and standardised the Bengali version of the package which is widely being used, mainly in the rural areas. The out-put is commendable.

**CBR (Community Based Rehabilitation):** This is a home based programme where field workers with basic training teach families and their disabled member's basic rehabilitation techniques (Hoel *et al.* 1988).



CBR is recognized by increasing number of national and international authorities to be the most realistic and desirable approach to the enormous scale of disability in the developing world. WHO estimates 500 million people in the world, (or approximately one in ten) are disabled as a consequence of mental, physical or sensory impairment (Jones, 1988).

The CBR priority is simply expressed as "Rehabilitation reaching the majority of the disabled people in their own home and communities". And the CBR worker's role is to "mobilize people and to see what their needs are". CBR should provide the needed alternative to journeying to a large, probably distant, institution for treatment. This could enable disabled people to become self-reliant and trusted by their communities. Families also benefit when the disabled children become useful, they are appreciated and it releases pressure on the family as a whole.

Though not recognized as a formal and official programme of the NGOs and Government, there are some programmes of some NGOs in the villages of Bangladesh which are somewhat like the CBR programme. These NGOs have trained their field workers at BIMR about the basic concepts of Mental Retardation in addition to their main training on rural development. These field workers have enlisted the mentally handicapped children and assessed their problems and prospects. The handicapped persons and their families were given specific programmes of training which will enable the disabled persons to engage in the family trade in their adulthood. In the informal way such attempts were always present in this country but now it is being supervised and appraised by the field workers of the NGOs. And the progress is satisfactory. The concerned families are now trying to train their children in the agricultural works, agro-based cottage industries, handicraft, pottery, poultry, etc. Before the advent of the field workers, these families were not serious about these handicapped children. Now the families know that it is possible to make the handicapped children self-sufficient.

Mittler (1989), Ex President of the International League of Societies for Persons with Mental Handicap (ILSMH), in his research paper entitled Meeting the needs of adolescents and young adults with learning difficulties concluded that there are no

simple prescriptions for meeting the needs of adults. It is not enough to advocate that all services should be community based or they should be based on principles of normalization or social role valorization. People can be isolated and lonely in the community, even more than in an institution. They can also be victimized and discriminated against. Above all, they, like all of us, need human companionship and support.

Many scientific investigations on mental retardation are being carried out throughout the world. These investigations are concerned mainly with the prevalence and assessment of mental retardation, the aetiology and treatment of mental retardation, and rehabilitation programmes for the mentally retarded persons.

The biological work on the aetiology of mental retardation was done by Pornswan Wasant at the Faculty of Medicine, Siriraj Medical School, Mahidol University of Thailand. Wasant (1989) found that the etiologies of mental retardation can be divided into genetic and non genetic categories. The genetic causes are chromosomal. Nongenetic etiologies are those that occur in prenatal, perinatal and postnatal period. The clinical evaluation of a child with mental retardation includes detailed pregnancy history, developmental and family history and the clinical examination of the child. Thus the multidisciplinary approach is often necessary. The outstanding recent advances in the field of molecular biology, biochemistry and molecular genetics (gene mapping, recombinant DNA technology) and prenatal diagnosis of chromosomal and biochemical genetic disorders give much hope in the prevention and treatment of mental retardation.

Marfo *et al.* (1986) have concluded that children in developing countries are extremely vulnerable to many adverse biological and environmental factors which cause handicap conditions. The principal causes of childhood disability in these countries are related to such factors as malnutrition, poor medical care and preventive measure that adversely affect children and pregnant mothers.

Assessment of people with mental retardation is one of the big problems for the persons engaged in the services for the mentally retarded persons from the very beginning. Lot of recommendations and proposals have been given by different authors. Hogg and Raynes

(1987) have mentioned that four broad classes of approach to assessing people with mental handicap can be suggested: (1) norm referenced; (2) assessment of adaptive behaviour; (3) criterion referenced; (4) techniques of behavioral observation.

Oura (1989) of the Osaka City Rehabilitation Centre of Japan in his study entitled 'Early diagnosis and treatment' said that Chorionic villi sampling offers several advantages over amniocentesis in terms of early diagnosis at 9 gestational weeks in comparison to 16 weeks in amniocentesis, chromosome analysis without culture, sufficient amount of samples for DNA analysis. Indication of prenatal diagnosis still is a centre of hot debates, because positive result leads to artificial termination of pregnancy in most cases.

Social factors of Mental Retardation attracted interest of many researchers in the western countries. Baratz and Baratz (1970), Herzog and Lewis (1970) and Hurley (1969) have investigated the relationship between poverty and Mental Retardation. The American President's Committee on Mental Retardation (1970) pointed out the existence of a large number of Mentally Retarded children who live in the slums of USA. Eisenberg (1969) observed the effects of poor environment, lack of stimulation, etc. on Mental Retardation.

Recently the professionals engaged in the research work in this area in developed countries are mainly interested to evaluate the effectiveness of various techniques and methods used for the upliftment and rehabilitation of the mentally retarded persons.

Yeargin-Allsopp *et al.* (1995) assessed differences in the prevalence of mild mental retardation, defined as an Intelligence Quotient (IQ) from 50 to 70, between Black and White children. A case-control study design was used. Ten-year-old children with mental retardation were identified from multiple sources. Information on race, sex, maternal age, birth order, economic status, and maternal education was abstracted from birth certificates of 330 case children and 563 control children (public school students). The crude Black-White odds ratio (OR) was 2.6, but it was reduced to 1.8 after the other five covariates were controlled. The disparity was largest among children whose mental retardation was first diagnosed when they were 8 to 10 years old (adjusted OR=2.5). They found no significant difference in the occurrence of mild

mental retardation between Black and White children diagnosed before the age of 6 years (adjusted OR=1.2). Black children had a higher prevalence of mild mental retardation within all strata of the other five covariates. Five socio-demographic factors accounted for approximately half of the excess prevalence of mild mental retardation among Black children. Possible reasons for the residual difference are discussed.

Drews *et al.* (1996) observed that smoking has been linked to small cognitive, achievement, and behavioral deficits but have not been associated with more severe cognitive impairments. This investigation evaluated the relationship between maternal smoking during pregnancy and idiopathic mental retardation (MR). Data on maternal smoking during pregnancy were obtained during face-to-face interviews with the mothers of 221 children with idiopathic MR and the mothers of 400 children attending public school. All children had been born in the five-county metropolitan Atlanta area in 1975 or 1976 and were living in the area when they were 10 years of age. They used exposure odds ratios (ORs) to assess the relationship between maternal smoking and MR, controlling for sex, maternal age at delivery, race, maternal education, economic status, parity, and alcohol use. Maternal smoking during pregnancy was associated with slightly more than a 50% increase in the prevalence of idiopathic MR (adjusted OR, 1.6; 95% confidence interval, 1.0-2.4), and children whose mothers smoked at least one pack a day during pregnancy had more than a 75% increase in the occurrence of idiopathic MR (OR, 1.9; 95% confidence interval, 1.0-3.4). This increase was neither accounted for by other socio-demographic risk factors for MR nor explained by an increase in the prevalence of low birth weight among the children of smokers. They suggest that maternal smoking may be a preventable cause of mental retardation.

Decoufle *et al.* (1993) conducted a case-control study to examine relationships between potential risk factors in women's prenatal occupational histories and subsequent mental retardation in their 10-year-old children. Children with mental retardation (intelligence quotient less than 71) were identified from special education records maintained by the public school systems in the metropolitan Atlanta area and

from records of various medical and social service agencies serving children with special needs. Control children were chosen from the rosters of 10-year-olds who were enrolled in regular education classes in the local public school systems. To obtain occupational histories, socio-demographic data, and other information, we interviewed 352 natural mothers (67%) of 525 case children and 408 natural mothers (64%) of 636 control children. They computed odds ratios for each of 25 selected occupation, industry, and agent categories controlling for maternal education, birth order, and race. Most comparisons yielded odds ratios that were not indicative of unusual risks, but they found lower than expected risks among children of teachers and health-care professionals. They also found a strong, positive association between mental retardation and maternal employment in the textile and apparel industries. The findings are useful for planning the direction of future studies of childhood cognitive ability to focus on specific parental occupations or industries.

Decoufle and Boyle (1995) conducted another case-control study of mental retardation in which Children (aged 10 years) were identified from existing records at multiple sources, primarily the public school systems. Control Children were drawn from a roster of public school students not receiving special education services. They found that maternal educational level at the time of delivery was strongly and inversely related to a form of mental retardation not accompanied by other serious neurological conditions. For this isolated form of mental retardation, maternal educational level was by far the most important predictor from among seven socio-demographic variables examined. There was a significant race-education interaction that indicated a steeper gradient in risk among white mothers than among black mothers. Relative to children of white mothers with 12 years of education, all children of black mothers, except those whose mothers had 16 or more years of education, were at increased risk.

Williams and Decaufle (1999) observed that whether older or very young maternal age at delivery is associated with mental retardation in children. Ten-year-old children with mental retardation (an intelligence quotient of 70 or less) were identified in 1985-1987 from multiple sources in the metropolitan Atlanta, Georgia, area. These

children were subdivided into two case groups according to whether they had concomitant developmental disabilities or birth defects affecting the central nervous system (co-developmental retardation) or did not have such disabilities (isolated retardation). Control children were randomly chosen from the regular education files of the public school systems in the study area. Data on socio-demographic variables were gathered from birth certificates. Children of teenaged mothers were not at increased risk for either form of retardation and children of mothers aged  $>$  or  $=30$  years were not at increased risk for isolated retardation, in comparison with children of mothers aged 20-29 years. A markedly elevated risk of co-developmental retardation was seen among black children of mothers aged  $>$  or  $=30$  years that was not attributable to Down syndrome. A modest increase in risk for co-developmental retardation was observed among white children born to older mothers, but it was entirely due to Down syndrome.

Mervis *et al.* (1995) studied a case-control study to assess the association between low birth weight and mental retardation (Intelligence Quotient  $<$  or  $= 70$ ) among 10-year-old children who were born in 1975 or 1976. Data from the population-based Metropolitan Atlanta Developmental Disabilities Study were used in this study. Children with mental retardation were identified from existing records at multiple sources and control children were selected from public school rosters. Data on birth weight and other covariates (sex, birth order, maternal age, maternal race, maternal education and gestational age) came from birth certificates. They used multiple logistic regression modeling to obtain adjusted odds ratios for mental retardation, with normal birth weight children (those weighing  $>$  or  $= 2500$  g) as the referent group. For low birth weight children as a whole, the odds ratio for mental retardation was 2.8 (95% CI 1.9-4.2). The risk was higher for very low birth weight ( $< 1500$  g) children than for moderately low birth weight (1500-2499 g) children, and higher for severe mental retardation (intelligence quotient  $< 50$ ) than for mild mental retardation (intelligence quotient 50-70). Adding gestational age to the models revealed that normal birth weight children who were born preterm also were at increased risk of having mental retardation at age 10 years.

Decoufle and Autry (2002) in their study of a population-based cohort of 10-year-old children with mental retardation, cerebral palsy, epilepsy, hearing impairment or vision impairment, who were ascertained at 10 years of age in a previous study conducted in metro Atlanta during 1985-87, was followed up for mortality and cause of death information. They used the National Death Index to identify all deaths among cohort members during the follow-up period (1985-95). They estimated expected numbers of deaths on the basis of actual age, race and sex specific death rates for the entire Georgia population for 1989-91. The objective was to quantify the magnitude of increased mortality and evaluate the contribution of specific disabilities to mortality among children and adolescents with one or more of five developmental disabilities. A total of 30 deaths were observed; 10.1 deaths were expected, yielding an observed-to-expected mortality ratio of almost three to one. The numbers of observed deaths exceeded those of expected deaths, regardless of the number of disabilities present, but the ratios were statistically significant (at the 95% confidence level) only in children with three or more co-existing disabilities. In general, the magnitude of the mortality ratios was directly related to various measures of the severity of the person's disability. An exception to this pattern was the elevated mortality from cardiovascular disease among cohort members with isolated mental retardation (three observed deaths vs. 0.2 expected). The specific underlying causes of death among other deceased cohort members included some that were the putative cause of the developmental disability (*e.g.* a genetic syndrome) and others that could be considered intercurrent diseases or secondary health conditions (*e.g.* asthma). Prevention efforts to decrease mortality in adolescents and young adults with developmental disabilities may need to address serious conditions that are secondary to the underlying disability (*i.e.* infections, asthma, seizures) rather than towards injuries, accidents and poisonings, the primary causes of death for persons in this age group in the general population.

Holland (2000) in his paper "Ageing and learning disability" mentioned that ageing is a continuation of the developmental process and is influenced by genetic and other biological factors as well as personal and social circumstances. The research was designed to identify some key biological, psychological and social issues relevant to

how ageing might particularly affect people with learning disabilities. This selected review considers the extent to which there are similarities and differences relative to people without learning disabilities. It was found that there is a convergence, in later life, between people with a learning disability and those without, owing to the reduced life expectancy of people with more severe disabilities. People with Down's syndrome have particular risks of age-related problems relatively early in life. He concluded that improved life expectancy of people with learning disabilities is well established. There is a lack of a concerted response to ensure that the best possible health and social care is provided for people with learning disabilities in later life.

Moss *et al.* (2000) in their paper "Psychiatric symptoms in adults with learning disability and challenging behaviour" studied people with learning disability as one of the most frequent reasons for psychiatric referral. The study was designed to determine what proportions of people with challenging behaviour actually have psychiatric symptoms. Using an instrument specifically designed for use by informants, a sample of 320 people with administratively defined learning disability, with and without challenging behaviour, was surveyed for the presence of psychiatric symptoms. It was found that increasing severity of challenging behaviour was associated with increased prevalence of psychiatric symptoms, depression showing the most marked association. Anxiety symptoms were associated with the presence of self-injurious behaviour. Finally they concluded that there is clearly the potential for reducing challenging behaviour by improved identification and treatment of coexisting psychiatric disorders. The possibility of modifying diagnostic criteria for depression in people with learning disability, by including aspects of challenging behaviour, merits attention.

Bradley *et al.* (2002) in their paper "Mental Retardation in Teenagers: Prevalence Data From the Niagara Region of Ontario" identified 255 individuals as having mental retardation (IQ=75). Of these, 171 chose to participate (defined as "participants with mental retardation"; the remaining 84 were "non participants with mental retardation"). Thus, the participation rate was 67% (171/255). Participants and non participants with mental retardation did not differ on age, sex, or IQ, although



there were more non participants in the lower social strata. Overall prevalence for MR was 7.18/1000. For mild mental retardation (MMR; that is, IQ = 50 to 75), prevalence was 3.54/1000, and for severe mental retardation (SMR; that is, IQ < 50), it was 3.64/1000. They concluded that the prevalence estimate for SMR is similar to rates from previous studies conducted worldwide. Their estimate for MMR parallels the lower rates found in Scandinavian countries and contrasts with the higher rates generally reported in the US.

Matsuishi *et al.* (1997) studied a case of "Ring 13 Syndrome" in an 18-year-old male with particular focus on mental retardation. The clinical picture was characterised by mild mental retardation, microcephaly, large low set ears, a broad nasal bridge, epicanthus, micrognathia and short philtrum. A review of the literature with a focus on mental retardation concluded that descriptions of mental retardation were often unqualified and at times ambiguous. Furthermore, in contrast to the characteristic description of Ring Chromosome 13 Syndrome this describes marked mental retardation of a small number of cases with mild mental retardation.

Matsuishi and Millar (1998) in their article "The chromosome 9p syndrome with microgenitalia" report an 18-year-old male who is the third child of healthy and unrelated parents. The mother and father were 28 and 31 years old respectively at birth. The proband has twin elder sisters both of whom are healthy. The third pregnancy was terminated by elective abortion. The proband was born at 42 weeks after an uneventful pregnancy. Birth weight was 4000g, length was 53cm and head circumference was 37cm. Early developmental milestones were slightly delayed: Head control was achieved at 6 months, sitting at 8 months, and first step taken at 1 year and 3 months. Medical history reports undescended testes which resolved spontaneously. The proband attended a remedial class in both elementary and junior high school. For high school he was transferred to a special school. On evaluation at 18 years old he scored 30 on the Tanaka Binet Intelligence test, this is the Japanese version of the Binet test. On examination at age 18 he presented with a head circumference of 56cm. Morphological anomalies included webbed neck, flat occiput, broad nasal bridge, anteverted nostrils, narrow palpebral fissures, hypertelorism and

epicanthic folds. His mouth was small with a protruding lower lip, thin upper lip and a high arched palate. His ears were low set ears with abnormal lobules. Other dysmorphic features included long philtrum, micrognathia and retrognathia. He had a thoracic kyphosis and a long middle phalanx. Microgenitalia was characterised by a small penis (4cm stretched), small testis and sparse pubic hair. Neurological findings included hypotonia, intention tremor, dysarthria, and exaggerated deep tendon reflexes particularly on the left side. CT scan revealed agenesis of the corpus callosum.

Yoshida *et al.* (2002) in their article "An Epidemiological Study on the Cause of Mental Retardation in Yokohama City" mentioned the cause of mental retardation of 337 individuals seeking healthcare services at the Yokohama City Social Welfare Center for Disabilities during a period of a year and a half, from October 1987 to March 1989. The total number of participants in the study was 337 and consisted of 207 males and 130 females. Age ranged from 14 to 58 years with an average age of 22 years. IQ was evaluated using the Tanaka-Binet test. Individuals with an IQ under 50 were classified as having severe mental retardation and those with IQs between 51 and 70 were classified as having mild mental retardation, in accordance with international standards. The number of cases with severe mental retardation was 262 and 75 cases presented with mild mental retardation. Physical and neurological examination was performed in all cases in an attempt to ascertain the causes of mental retardation. Only when deemed necessary by the attending physician, and if parental consent was granted, electroencephalogram, brain CT scan, and chromosome analysis were carried out. In cases where the diagnosis had already been established, past medical records were consulted. The results of the study were compared to results of a very similar study published by the University of Kuopio in eastern Finland. The time of insult was categorized into four groups: prenatal, perinatal, postnatal and uncertain. In the severely mentally retarded group, the time of insult was considered to have occurred in the prenatal period in 25.6% of cases, in the perinatal period in 9.2% of cases, in the postnatal period in 8.0% of cases and was uncertain in 57.2% of cases. In the mildly mentally retarded group the insult occurred in the prenatal period in 14.7% of cases, in the perinatal period in 8.0% of cases, in the postnatal period in 12.0% of

cases, and was uncertain in 65.3% of cases. In the mildly mentally retarded group, familial association was recognized in 27% of cases. The Finland study revealed similar patterns. Both studies demonstrated that most individuals with severe mental retardation and a determinable cause have genetic and chromosomal abnormalities. According to Yoshida, the cause of mental retardation was harder to determine in individuals with mild mental retardation, and most of those with an uncertain cause had a positive family history. However, the above findings point out the need for prenatal diagnosis and genetic counseling in certain cases, requiring careful attention to ethical issues.

Thompson and Reid (2002) in their article "Behavioural symptoms among people with severe and profound intellectual disabilities: a 26-year follow-up study" mentioned that very little is known about the natural history of challenging behaviour and psychiatric disorder in people with severe and profound degrees of intellectual disability. To clarify the natural history of challenging behaviour and psychiatric disorder in this population through a long term prospective cohort study over a 26-year period. One hundred individuals with severe or profound intellectual disability were randomly selected in 1975. Their behaviour was recorded through carer and psychiatrist ratings using the Modified Manifest Abnormality Scale of the Clinical Interview Schedule. The presence and severity of psychiatric disorder were also recorded. The study was repeated in 1981/82 and 1992/93. They repeated the study again in 2001, supplementing the original observational data with the Checklist of Challenging Behaviour. They found that behavioural symptomatology is remarkably persistent, particularly stereotypy, emotional abnormalities, eye avoidance and over activity, although the severity of overall psychiatric disorder does show some abatement through time. Finally they concluded that these findings influence the prospects of success in relocating adults with severe and profound degrees of intellectual disability back into the community.

Cuthill *et al.* (2003) in their paper entitled "Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability" mentioned that there is no reliable and valid self-report measure of depressive symptoms for

people with learning disabilities. To develop a scale for individuals with learning disability, and a supplementary scale for carers, the items were generated from a range of assessment scales and through focus groups. A draft scale was piloted and field-tested using matched groups of people with or without depression, and their carers. The scale was also administered to a group without learning disabilities for criterion validation. Finally they found that the Glasgow Depression Scale for people with a Learning Disability (GDS -LD) differentiated depression and non-depression groups, correlated with the Beck Depression Inventory-II ( $r=0.88$ ), had good test-retest reliability ( $r=0.97$ ) and internal consistency (Cronbach's  $\alpha=0.90$ ), and a cut-off score (13) yielded 96% sensitivity and 90% specificity. The Carer Supplement was also reliable ( $r=.98$ ;  $\alpha=0.88$ ), correlating with the GDS -LD ( $r=0.93$ ) they concluded that both scales appear useful for screening, monitoring progress and contributing to outcome appraisal.

Hauser-Cram *et al.* (1999) investigated the extent to which the family environment predicted differences in trajectories of adaptive development in young children with Down syndrome. The sample was comprised of 54 children with Down syndrome and their families who were studied from infancy through the age of 5 years as part of a longitudinal study of children with disabilities. Hierarchical linear modeling (HLM) was used to estimate the parameters of hierarchical growth models in domains of adaptive development. Results indicated that growth in communication, daily living skills, and socialization domains were predicted by measures of the family environment (i.e., family cohesion and mother-child interaction) above and beyond that predicted by maternal education. Further, Bayley MDI measures during infancy did not predict changes in adaptive development in any of the domains. The results are discussed in terms of implications for service provision and for expanding theoretical frameworks to include the development of children with disabilities.

Seltzer *et al.* (2001) studied family involvement with adults who have mental retardation following a residential transition to a non parental living situation was examined. They found that aging mothers were highly involved in the relocation process and had frequent contact and continued emotional involvement with their

adult child. Mothers became increasingly satisfied with their level of contact with their child over time, less worried about the future, and had decreasing levels of direct care giving and contact with residential staff. Adult siblings reported improved sibling relationships over time. Siblings whose brother or sister moved out of the parental home increased their shared activities and felt less pessimistic about the future. Findings address a critical gap in knowledge about the life course roles of families of persons with mental retardation.

Hodapp *et al.* (2003) examined the nature and correlates of stress in mothers of children with Down syndrome. In the first part of their study, they compared 27 mothers of children with Down syndrome with 15 mothers of children with heterogeneous causes of learning difficulty. Using Abidin's (1995) Parenting Stress Index (PSI), mothers in the Down syndrome group reported lower total child-related stress levels, particularly concerning the degree to which the mother considers the child acceptable and reinforcing. In the second part, we identified predictors of stress in mothers of children and adolescents with Down syndrome ( $N = 37$ ). Children's behaviour problems related to higher levels of overall and specific domains of child-related stress, and children who were reported as being more cheerful and outgoing had parents who judged their offspring as more acceptable and reinforcing. Mothers also rated their children as less reinforcing when offspring were older.

Yoshida *et al.* (1997) carried out a research to assess the administrative management of people with mental retardation, the results of medical diagnosis, psychological testing and testing of working capacity from October 1987 to March 1989 in the social welfare center for disabilities of Yokohama city. The total number of cases with mental retardation in this survey was 377. Male: female ratio of mental retardation was 1.73: 1, the average IQ was 39.0. The percentage of mildly mentally retarded was 20.8%, 30% for moderate, 25.1% for severe and 20.2% for profound. These result shows that the rate for severely retarded is more than that previously presented. The most prevalent complication was epilepsy with 28% of cases being affected. Using anti-epileptics their condition was generally controlled. The prevalence rate of epilepsy was proportional to the degree of mental retardation. Male: female ratio of

mentally retarded with autistic disorder was 7.7: 1. The percentage of autistic disorder in the total group was 16%. The average IQ of this group was 42.4. Generally speaking, the more severe degree of mental retardation that the higher prevalence of autistic disorder. Those with mild mental retardation showed maladjustment at a higher rate. As for the administrative management on the basis of these results, the group of profound and severe mentally retarded tended to be institutionalized and the group of moderate and mild mentally retarded attended a vocational aid center. The shortage of institutions is a serious problem in Yokohama city. Considering of higher rate of severely mentally retarded, construction of institutions is urgent. In addition to that, we emphasize the need for special consideration for those with autistic disorder.

Sarimski (2003) in his article "early play behaviour in children with 5p- (Cri-du-Chat) syndrome" analyzed mental level, and complexity and style of play were analyzed in 10 children who were homogeneously selected with respect to their chronological age (range = 2-7 years). A high rate of distractability and a low level of object-directed behaviours were observed in the play sessions. The findings were compared to two comparison groups (subjects with Down's syndrome or Cornelia-de-Lange syndrome) matched for mental age in order to analyse the specificity of these behavioural features for young children with 5p-S. He concluded that a low level of object-directed behaviours may be an early precursor of hyperactivity, distractability and stereotypy, which have been reported to be the characteristic features of the behavioural phenotype of older individuals with 5p-S.

Gustafsson and Sonnander (2002) in their article "Psychometric evaluation of a Swedish version of the Reiss Screen for Maladaptive Behavior", They used a Swedish version of the Reiss Screen for Maladaptive Behavior (RSMB), an instrument used for identification of mental health problems in people with intellectual disability (ID) was evaluated in terms of inter-rater agreement, internal consistency, item grouping and criterion validity based on a random sample and a clinical group of adults with ID. The Swedish version of the RSMB had moderate-to-low inter-rater agreement on specific items and good internal consistency. The total score was considered to be a fairly reliable measure of a positive or negative result on the RSMB. A principal

component analysis yielded seven interpretable components. A close resemblance in sets of items between the Swedish version and the original version of RSMB was found for three subscales: Aggressive Behaviour, Avoidance Disorder and Depression (Behavioural Signs). The outcome of the criterion validity analysis indicated a higher rate of false negatives than false positives. The potential influence of concurrent psychopharmacological treatment is discussed. They concluded that the Swedish version of the RSMB can be used as intended by staff as a primary screening device for the identification of mental health problems among people with ID in a Swedish setting.

Dykens *et al.* (2002) in their paper "Maladaptive behaviour in children and adolescents with Down's syndrome" examined age-related changes in the maladaptive behaviours of 211 children and adolescents with Down's Syndrome aged between 4 and 19 years (mean = 9.74 years). Most participants ( $n = 180$ ) were recruited from families residing in the greater Los Angeles area, California, USA, while a minority ( $n = 31$ ) were patients from a clinic specializing in the psychiatric management of people with Down's Syndrome. The participants were divided into four age groups: (1) 4-6 years, (2) 7-9 years, (3) 10-13 years and (4) 14-19 years. Externalizing behaviours were lower across both the community and clinic samples, while internalizing behaviours were significantly higher in older adolescents aged between 14 and 19 years. Increases were found in withdrawal, seen in 63% of community-based adolescents, and 75% of clinic adolescents. They concluded that older adolescents with DS may show decreased externalizing symptoms and subtle increases in withdrawal. Possible relationships are discussed between these shifts and increased risks of later-onset depression and Alzheimer's disease in adults with Down's Syndrome.

Niccols *et al.* (2003) in their article "Mastery motivation in young children with Down's syndrome: relations with cognitive and adaptive competence" studied on relations between motivation and competence have focused on cognitive competence, despite theoretical predictions that mastery motivation spurs behaviour that is effective in meeting the demands of one's environment, *i.e.* adaptive competence.

Issues of adaptive competence are especially relevant for children with developmental delay since functional independence is an important long-term goal for these children. In this study, mastery motivation was examined in relation to both cognitive and adaptive competence in 5-year-old children with Down's syndrome ( $n = 41$ ). Scores on mastery task and parent-report measures of mastery motivation were generally low, but positively related to scores on standardized measures of cognitive competence and adaptive competence. They concluded that this is the first study of motivation-competence relations in pre-school-age children.

Arvio and Sillanpää (2003) in their study entitled "Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland", the aim of this study was to describe the aetiology, associated impairments and prevalence of severe and profound intellectual disability (SPID) in Finland. The number of people with SPID in the catchment area of the Pääjärvi Centre for the Mentally Retarded, Lammi, Finland, (total population = 341 227) was calculated from the client register of this centre. Aetiological factors and background diagnoses for all subjects with SPID were analysed retrospectively. The number of people with SPID was 461, giving a prevalence of 0.13%. The aetiology of their SPID was genetic or congenital in 235 (50.9%) individuals, acquired in 89 (19.3%), genetic and/or acquired in 84 (18.3%), and unknown in 53 (11.5%) subjects. Out of the 53 individuals with an SPID of unknown origin, 48 (90.6%) had an associated impairment; the remaining five were the only members of the study group showing normal growth, and having neither dysmorphic features, physical abnormalities nor family members with ID. Out of the 461 subjects, 422 (91.5%) had between one and six associated impairments (total = 954), and the remaining 39 (8.5%) had SPID as their only impairment. Uncomplicated SPID was mainly of genetic or congenital origin, whereas all subjects with acquired encephalopathy had multiple disabilities. Speech defects, epilepsy and cerebral palsy were the most common associated impairments. They concluded that severe and profound ID almost always occurs concomitantly with other severe neurological or psychiatric impairments. The proportion of people with SPID described in the present study is similar to that found in Finland in 1966. The aetiology of SPID in the vast majority of cases is biopathological.



Mason and Murphy (2002) in their article "Intellectual disability amongst people on probation: prevalence and outcome" studied on 90 people on probation in south-east England were screened using the Learning Disabilities in the Probation Service (LIPS) screening tool, which was designed to be used by probation officers to identify those with possible ID. The LIPS incorporates two measures of cognitive functioning: (1) the Quick Test (QT); and (2) the Clock Drawing Test (CDT). Seven per cent of participants were found to have QT IQs and CDT scores 1.6 SD below the mean. When compared to those who appeared to be functioning within the normal range, those with possible ID were found to be significantly younger. However, no differences were found between the two groups in terms of the final outcome of the probation order. It seems likely that the probation service contains a significant minority of people with ID. Despite the fact that no difference was found to exist in terms of outcome, people with ID or borderline ID are likely to have a number of support needs which could affect the success of their time on probation.

McIntyre *et al.* (2002) in their article "Behaviour/mental health problems in young adults with intellectual disability: the impact on families" studied the impact of dual diagnosis [*i.e.* intellectual disability (ID) and mental disorder] in young adults on their mothers' perceived levels of stress and decisions about placement. The mothers of 103 young adults with severe ID were interviewed using a 2-3-h in-depth protocol of measures designed to assess their child's adaptive functioning, maladaptive behaviour, mental health problems and negative impact on the family, as well as their own thoughts on out-of-home placement. The Scales of Independent Behavior - Revised Problem Behavior Scale assessed problem behaviours and the Reiss Screen assessed mental disorder. These measures were highly correlated ( $r=0.64$ ), but tapped some different domains of maladaptive behaviour and proved to be most predictive when employed together. Behaviour and/or mental health (B/MH) problems significantly predicted the mothers' perceived negative impact of the young adult on the family, even after controlling for other young adult characteristics. These problems also predicted the family's steps toward seeking out-of-home placement, as did better young adult health and the mother's higher educational attainment; stress did not predict additional variance in placement once these variables were accounted for.

Ashman *et al.* (1995) in their article "Employment, retirement and elderly persons with an intellectual disability" which is a National Australian study of people with intellectual disability of 55 years of age and over investigated their employment and retirement patterns, attitudes to work and retirement, and the degree to which they were involved in leisure or recreational programmes. Two cohorts were recruited: one included all known members of the target group who agreed to participate in the study in the states of Queensland and Western Australia; and the second was a proportional, random sample drawn from a national database on a state population basis. A large number of the participants had never been involved in full- or part-time employment, either in a competitive or supported environment, or in workshops. The majority of those who had worked expressed strong positive attitudes toward employment and concern about retirement, suggesting the need for pre-retirement programmes including transition and choice-making skills to prepare participants for the future.

Rousey *et al.* (2002) in their article "Stability of measures of the home environment for families of children with severe disabilities" investigated the stability of home environment in families of children with severe disabilities. Sixty-four families were assessed at three time points regarding aspects of their home environment. Family environment scale, Home Quality Rating Scale (HQRS) and home observation for measurement of the environment scores were collected at 7 and 9 years after the initial assessment. A remarkable degree of stability was observed, particularly for the FES. The median change score was zero for most subscales; no correlations differed significantly between the 7-and-year retests. A repeated measure MANOVA found a significant change in scores over time for only one subscale of the HQRS but none of the 10 FES subscales. Results suggest that, for the FES, administration of these measures every 2 years, perhaps less often, would be sufficient in longitudinal studies of this population. Internal consistency reliability of the FES was lower for these families than in the standardization samples, emphasizing the need to validate measures used with special populations.

Greenberg *et al.* (1997) in their article "The Differential Effects of Social Support on the Psychological Well-being of Aging Mothers of Adults With Mental Illness or

Mental Retardation” mentioned that aging mothers of adults with mental illness and aging mothers of adults with mental retardation compared their levels of stress, social support resources and the extent to which social support was predictive of their level of care giving burden and depressive symptoms. Although mothers of adults with mental illness had smaller social support networks than mothers of adults with mental retardation, they were more likely to be members of support groups and at least one friend also caring for a relative with disabilities. In addition, social support was a more prominent predictor of changes in burden and depressive symptoms in mothers of adults with mental illness, suggesting the importance of the social context for their psychological well-being.

CDC in the mid-1980s studied as part of the Metropolitan Atlanta Developmental Disabilities Study (MADDS), which studied how common certain disabilities were in 10-year-old children. They found that 12 of every 1,000 10-year-old children had mental retardation. Mild mental retardation was 3 times more common than severe mental retardation.

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP, 1991-1994) found that mental retardation was more common in older children (ages 6-10 years) than in younger children (ages 3-5 years). Mental retardation was also more common in boys than in girls, and more common in black children than in white children in United States.

Rachel *et al.* (2001) in their study “Birth Weight and School-age Disabilities: A Population-based Study”, found that mortality rates have declined for low birth weight and extremely low birth weight infants. Yet, the consequences of survival for these children may be adverse developmental outcomes. Few studies to date have examined school-age outcomes for these children. The participants in this study represented a population-based cohort of Florida children who were born between 1982 and 1984 and who were receiving a public school education in 1996–1997. Linkage methodology was used to establish a cohort of 267,213 children aged 12–15 years with both birth certificate and school records. Birth weights were stratified into 500-g increments beginning with 999 g; 17% of the population had some school-

identified disability. Risk ratios for specified school-identified disabilities increased as birth weight decreased for all birth weight strata of  $\geq 3,499$  g. Narrow increments of birth weights may better portray a more accurate estimate of risk for infants born at extremes than the conventional definition of  $< 2,500$  g.

Durkin *et al.* (1998) in their paper "Prevalence and correlates of mental retardation among children in Karachi, Pakistan" reports estimates of the prevalence of mental retardation and associated factors based on a population survey of 2- to 9-year-old children in Greater Karachi, Pakistan. A two-phase survey was implemented during the years 1988-1989. In the first phase, a cluster sample of 6,365 children (5,748 from urban areas and 617 from rural areas) was screened for disabilities using a parental report known as the Ten Questions instrument. In the second phase, all children with positive screening results and a 10% sample of those with negative results were referred for structured medical and psychological assessments. Estimates of the prevalence of mental retardation were 19.0/1,000 children (95% confidence interval (CI) 13.5-24.4) for serious retardation and 65.3/1,000 children (95% CI 48.9-81.8) for mild retardation. Both estimates were considerably higher than respective prevalence estimates obtained in industrialized countries and in selected less developed countries. In this population, lack of maternal education was strongly associated with the prevalence of both serious (odds ratio = 3.26, 95% CI 1.26-8.43) and mild (odds ratio = 3.08, 95% CI 1.85-5.14) retardation. Other factors that were independently associated with mental retardation in Karachi included histories of perinatal difficulties, neonatal infections, postnatal brain infections, and traumatic brain injury, as well as current malnourishment. Further research is needed to assess the contribution of consanguineous marriage, improvements in child survival, and other factors to the unusually high prevalence of mental retardation in this population.

Carlos *et al.* (2003) examined the effect of social engagement on disability among community-dwelling older adults in 1982-1991. Data were collected from the New Haven, Connecticut, site of the Established Populations for Epidemiologic Studies of the Elderly. Baseline social engagement was measured by using 11 items related to social and productive activity. Disability data consisted of a six-item measure of

activities of daily living, a three-item measure of gross mobility, and a four-item measure of basic physical functions. Nine waves of yearly disability data were analyzed by using generalized estimating equations models. After adjustment for age, gender, race, and physical activity, significant cross-sectional associations ( $p$ 's < 0.001) were found between social engagement and all three measures of disability, with more socially engaged older adults reporting less disability. Social engagement also showed small, but negative interaction effects with follow-up-time outcomes ( $p$ 's < 0.01), indicating that the protective effect of social engagement decreased slightly during follow-up. Results suggest a strong, but not necessarily causal association of social engagement with disability. Promotion of social engagement may still be important for the prevention of disability.

Some research studies on mental retardation have been carried out in Bangladesh, too. Synopses of some important studies are cited below.

Zaman and Afroze (1979) studied the Risk factors related to Mental Retardation among children in Bangladesh. The research was a Pilot Study to find out pre-natal and post-natal physical and socio-cultural causes of mental retardation among a small sample of children in Bangladesh. A total of 30 cases of mental retardates were examined. Analysis of the data revealed that 56% of the subjects were moderately retarded. Genetic factors and prolonged labour were found as the main causes of retardation among the subjects. The higher educational level and higher socio-economic status of parents of the sample indicated that the study used a biased sample. It was concluded that survey studies need to be done with larger representative samples of children to find out the prevalence of mental retardation in Bangladesh.

Zaman and Ferial (1985) studied the Etiological factors of Mental Retardation in a rural area of Bangladesh. In this study 978 children and their mothers were interviewed belonging to 8 villages of Dhamrai Union of Dhaka district (24 miles from Dhaka City). Total number of household visited was 590. The study revealed that a number of disabilities and diseases such as night blindness, hearing problems, seizures, etc. were associated with mental retardation and there was a significant relation between levels of intelligence and nutritional status of the children in the rural areas of Bangladesh.

Zaman and Munir (1988) mentioned that birth asphyxia causes multiple disabilities among a large number of children in Bangladesh.

In another study, development of early intervention programme for the handicapped in Bangladesh, Zaman and Munir (1987) concluded that early intervention is, in fact, effective. The authors also recommended for the developments of clinic for early diagnosis, early intervention programmes, portage guide to early education, WHO training manual for the disabled, self help group in rural area, distance training package for the outreach, etc. in Bangladesh.

Zaman and Akhtar (1984) in their study entitled Effects of early and late intervention among retarded children: Bangladesh experience mentioned that a handicapped child is still considered as a stigma in the family. Majority of the parents due to prevailing attitude, superstition and ignorance tend to either hide their retarded child or continue to have higher expectation and pressurize the child to behave normally and finally become frustrated when their children fail to meet their demands. In such a situation the need to discuss and evaluate the effects of early and late intervention is specially significant in Bangladesh.

Zaman and Akhtar (1990) in their study entitled A comparative study of attitudes of mothers of MR children who have been working as special education teachers and those who have not been working found that the mothers who were involved in teaching, taking care and management of retarded children in special education classes had more positive attitude towards their own child by being more caring, loving, accepting and adhering to discipline etc. as compared to mothers who were not teachers. This study reveals a significant fact that mothers of retarded children if involved in the management of other retarded children understand mental retardation better and this help them in accepting their own child as well. This study also revealed that the teachers who were not mothers were slightly better in taking care, following curriculum, adhering to discipline and acquiring knowledge on mental retardation thus displaying more positive attitude as compared to teachers who were mothers. This study thus proves that counselling of the parents of mentally retarded children will be more effective, if the parents become involved in the management of other retarded children.

Zaman and Rahman (1982) in their study entitled A comparative study of attitudes and personality traits of mothers of mentally retarded children with and without intervention programmes revealed that the mothers of the mentally retarded with intervention have more liberal attitude even when compared to mothers of normal. It was also found that the mothers of mentally retarded children without intervention significantly overestimated the ability of the children as compared to mothers of retarded children with intervention.

Zaman *et al.* (1987) in their study Attitudes towards Mental Retardation in Bangladesh investigated the opinion of general people towards mental retardation. Results of the study indicated that the three categories of subjects (general public, specialists and parents of the mentally retarded) differed significantly in their attitude towards, and knowledge about the mentally retarded persons. Persons of specialist group were found to have their most scientific attitude. It was interesting to note that the parents of mentally retarded were more scientific in their knowledge and ideas than the general public. Furthermore, the results revealed that the general public and parents of the mentally retarded from urban areas had more positive attitude and awareness than that of the rural subjects.

Zaman and Ara (1989) in their study Comparison of main-streaming and special school system for mentally retarded children compared improvement of social behaviour of two matched groups of mentally retarded children attending a special school and a normal school. Gunzberg's Progress Assessment Chart was administered to assess the social behaviour of both groups before attending the school and after attending the school. The results indicated improvement in social behaviour of both the groups and no significant difference was found between the two groups.

Zaman (1990) carried out an investigation in five sites of Bangladesh with a view to validate the Ten Questions (TQ) with probes as a tool for screening childhood disabilities in communities where formal resources for disabled children are scarce, if available at all. The types of disability covered by the TQ are blindness, deafness, mental retardation, speech problems, epilepsy and movement disorders.

Play behaviour attracted attention of the professionals working in Bangladesh. Rumizuddin (1990) observed the play behaviour of the mentally retarded children for several years. He has mentioned two special sides of the games of the mentally retarded children. First, the mentally retarded children can not cope with the same age group and like to play with the younger children. Secondly, the mentally retarded children require help from others in constructive games as they lack in innovative capacity.

Games and sports for the mentally retarded children and adults attracted interests of the parents, professionals and the volunteers from the very beginning of the services for the mentally retarded in all the countries. The most challenging job of Special Olympics international was done by the US parents. Games and sports have special implications for mentally retarded children. The mentally retarded children obtain more benefit from games and sports than from special education classes. In games and sports the rate of concentration of the mentally retarded persons are much higher compared to the rate of concentration in special education. The rate is relatively higher in outdoor games compared to indoor games (Sufi, 1990).

Durkin *et al.* (2000) in their article 'Prenatal and postnatal risk factors for mental retardation among children in Bangladesh' evaluated that the contribution of prenatal, perinatal, neonatal, and postnatal factors to the prevalence of cognitive disabilities among children aged 2–9 years in Bangladesh. A two-phase survey was implemented in 1987–1988 in which 10,299 children were screened for disability. In multivariate analyses, significant independent predictors of serious mental retardation in rural and urban areas included maternal goiter (rural odds ratio (OR) = 5.14, 95% confidence interval (CI): 1.23, 21.57; urban OR = 4.82, 95% CI: 2.73, 8.50) and postnatal brain infections (rural OR = 29.24, 95% CI: 7.17, 119.18; urban OR = 13.65, 95% CI: 4.69, 39.76). In rural areas, consanguinity (OR = 15.13, 95% CI: 3.08, 74.30) and landless agriculture (OR = 6.02, 95% CI: 1.16, 31.19) were also independently associated with the prevalence of serious mental retardation. In both rural and urban areas, independent risk factors for mild cognitive disabilities included maternal illiteracy (OR = 2.48, 95% CI: 0.86, 7.12), landlessness (OR = 4.27, 95% CI: 1.77, 10.29), maternal history of pregnancy loss (OR = 2.61, 95% CI: 0.95, 7.12), and small for



gestational age at birth (OR = 3.86, 95% CI: 1.56, 9.55). Interventions likely to have the greatest impact on preventing cognitive disabilities among children in Bangladesh include expansion of existing iodine supplementation, maternal literacy, and poverty alleviation programs as well as prevention of intracranial infections and their consequences.

Mobarak *et al.* (2000) identified that the stress experienced by mothers of young children with cerebral palsy in Bangladesh and to determine predictive factors. They recruited 91 mothers of children with cerebral palsy ages 1.5 to 5 years as they sought services at an urban and a rural center for their children. Mothers were interviewed with the Self-Report Questionnaire and other family background and child behavior measures. The children were examined by a pediatrician and by a psychologist. Out of 91, 38 (41.8%) mothers were at risk for psychiatric morbidity. Significantly associated factors included living in the rural area within a poor family, with a relatively older child. The strongest predictor of maternal stress in multivariate analysis was child behavior problems, especially those related to burden of caring. They have concluded that ensuring practical help for mothers and advice on managing common behavior problems are important components of intervention, as they may directly help to relieve stress on mothers of young disabled children in developing countries.

Durkin *et al.* (1994) examined the reliability and validity of several hypothesized indicators of socioeconomic status for use in epidemiologic research, particularly in studies of child health in the less developed world. Population-based surveys of child health and disability were completed in Bangladesh and Pakistan using standard questionnaires designed to measure four domains of household socioeconomic status: wealth, housing, parental education and occupation. Test-retest data indicate moderate to excellent reliability of most of the socioeconomic indicators in both countries. Loadings from factor analyses of the survey data provide further evidence of the reliability of the data, and confirm that the questionnaire measures housing and wealth as distinct domains in both countries. Parental education and occupation are correlated with housing and/or wealth in these data sets. Bivariate logistic regression analyses

show that, although 11 of 12 dichotomous indicators of low socioeconomic status constructed from the data are predictive of child death in at least one of the four sub-populations studied (rural and urban Bangladesh, and rural and urban areas of Karachi, Pakistan), no single indicator is predictive of child death in all four sub-populations.

Davidson *et al.* (1994) have been studied and screened for serious childhood disability in communities in Bangladesh, Jamaica, and Pakistan, where community workers screened more than 22,000 children ages 2-9 years. All children who screened positive, as well as random samples of those who screened negative were referred for clinical evaluations. Applying comparable diagnostic criteria, the sensitivity of the screen for serious cognitive, motor, and seizure disabilities is acceptable (80-100%) in all three populations, whereas the positive predictive values range from 3 to 15%. These results confirm the usefulness of the Ten Questions as a low-cost and rapid screen for these disabilities, although not for vision and hearing disabilities, in populations where few affected children have previously been identified and treated. They also show that the value of the Ten Questions for identifying disability in underserved populations is limited to that of a screen; more thorough evaluations of children screened positive are necessary to distinguish true- from false-positive results and to identify the nature of the disability if present.

In 1990 a survey of 2576 children aged two to nine years was carried out in Dhaka, Bangladesh, by Zaman *et al.* (1990) as part of a collaborative study to test the validity of a questionnaire (the Ten Questions) for screening severe childhood disabilities in community settings. Approximately 7% of the children were positive on the screen and this rate was slightly higher in boys than girls. The sensitivity, specificity and negative predictive value of the Ten Questions were perfect or nearly perfect for severe and moderate (serious) disabilities. The positive predictive value was only 22% for serious disabilities, but 70% of children classified as false positives were found to have mild disabilities or other conditions (such as ear infections) for which early detection and treatment could be beneficial. No major age or gender differences in the validity of the questionnaire were apparent, but this finding needs additional study

and confirmation with studies based on larger samples. In general, the results indicate that the Ten Questions is a valid tool for screening serious disabilities in children and can potentially improve the efficiency of health services by reducing the number of children requiring attention from professionals. Future studies using the Ten Questions should foster greater attention to the dimensions of childhood disability as a public health problem in the less developed world.

Anisuzzaman and Sufi (1997) investigated the psychotropic drug dependence of twelve readily available adult mentally retarded persons of Rajshahi City during 1995-1996. Close observation and interviews were done. Out of 12 subjects, 5 were male and 7 were female, The age of the subject ranged between 18 and 42 years, Use of four psychotropic drugs was studied. Those were antipsyhotics, antianxiety, antidepressants and anticonvulsants. It was found that the mentally retarded persons possess indifferent attitude towards drugs and large majority of the subjects takes anticonvulsant in addition to some other psychotropic drugs. Motor incoordination, irritability, restlessness, impaired concentration, chronic convulsions and frequent changes of emotion were the main factors that led their family members to seek help of General Physicians who prescribed the drugs. In the later stages, the doses of the drugs were changed, mostly increased, by the guardians later and other non-medical persons also motivated them to change the doses. All the guardians tried to withdraw the drugs in different ways but failed. When the drugs were finally withdrawn, the subjects showed abnormal emotional changes and many physiological problems. On the basis of this study the researchers concluded that the mentally retarded persons were undergoing lots of trials and errors with the psychotropic Drugs.

Zami and Sufi (1997) in their paper "Treatment and Care of the Mentally Retarded Persons at Bagha Thana in Rajshahi District" mentioned that the total population of the Thana is 153, 931 and it is assumed that there are approximately 3,500 mentally retarded persons. All these mentally retarded persons live in their own families. The researchers studied 50 randomly selected cases of mental retardation. Their guardians were asked eight selected questions and the behavior of the children was closely observed. The age of the subjects ranged from 04 to 49 years. Among the subjects 34

were males and 16 were female. It was found that in all cases Allopathic, Homeopathy, Ayurvedic and Faith Healing were attempted. The nature of treatment depended on the socio-economic status of the families. Usually the treatments were done during childhood and were totally given up during adulthood. The severe and profound cases died within early childhood period suffering from diseases without proper diagnosis. The mild and moderately retarded cases survived and were cared by the family members. Out of 50 cases 19 were found to have reached their adulthood, others were children. Most of the adults were found to help their families and neighbours in household works without any wages. The children were found loitering in their neighborhood. The family members considered the subjects as useless persons and were not motivated to continue any treatment after childhood. However, in all cases it was found that the family members took total care of their mentally retarded members in their daily living activities. Such supports are given according to the status and abilities of the families.

Sufi (1997) closely observed about 2000 mentally handicapped persons during 1984-1996 at different places in Bangladesh. Out of them about 200 already died at different ages. Those who died were observed closely before their death. The treatment pattern, attitude of the members, available medical facilities, etc were also studied. In Bangladesh most of the profound and severely handicapped persons die within few weeks of their birth due to faulty treatment and ignorance of the concerned persons. Those who survive also experience a relatively shorter life span compared to the general population. The mild and moderately retarded persons possess chances to live longer. In the middle class families of the urban areas these persons are never encouraged to marriage and they experience many psycho-bio-social restrictions. The mentally retarded persons of higher socio-economic group are cared by hired staff inside their own parental homes and most of them experience a relatively longer life. Subjects of the poor families in urban areas have some chance of free movements and they sometimes beg at the roadside. On the other hand, the mentally handicapped persons in the rural areas have better scope of free movements, marriage and to lead independent life. All the urban and rural mentally handicapped persons who survive until their old age experience the biological problems of aging. The major biological

aspects are diabetes, gastro-intestinal ailments, respiratory problems, neurological problems, parkinson's disease and finally paralysis. Those who died after suffering the old age problems mostly died in paralytic conditions. The most severe problem, of the elderly mentally handicapped persons is that they can not narrate or communicate their real problems to others. The treatments are given considering the perception of others. They die without mentioning their real psycho-biological feelings and sufferings.

Hossain and Sufi (1997) observed and interviewed the family members of 106 randomly selected mentally retarded persons of different backgrounds in Tanore area during 1996-1997. Tanore is one of the Thanas under Rajshahi District in Bangladesh. Total area of this Thana is 115 square miles and the population is about 150,000 persons. It is assumed that 4,500 mentally retarded persons are there, Population comprises the Original Tribal (the converted Christians) and the believers of Natural Powers. Considering the economic conditions there are Upper Middle class, Lower Middle Class and the Poor people of all the three religions. About 65% percent people possess lands or own homes and the remaining 35% live in other's lands. There is no service programme of any kind from the Government or any Agency for the Mentally Retarded person anywhere inside the entire Thana. The Mentally Retarded persons live in their own families with their parents. After death of the parents, the siblings or the near relations take care of these persons. The social security pattern of the Muslim Mentally Retarded subjects were found similar like all other places of the country. The Hindu Mentally Retarded persons do not inherit their parental properties and live at the mercy of the other siblings. The fate of the Tribal subjects are determined by the Headman of their own tribal groups which were found different in different sub-tribes. Large majority of the mentally retarded subjects of all the categories were found engaged in agriculture oriented works. It was observed that through there was no service from any Agency or Government the lives of the subjects were in good harmony with the general population and apparently they were happy. The authors recommended for better medical care and introduction of some vocational training programme for the handicapped persons.

Wang *et al.* (1995) have used five strategies to evaluate the reliability and other measurement qualities of the Ten Questions screen for childhood disability in different culture. The screen was administered for 22,125 children, aged 2-9 years, in Bangladesh, Jamaica and Pakistan. The test-retest approach involving small subsamples was useful for assessing reliability of overall screening results, but not of individual items with low prevalence. Alternative strategies focus on the internal consistency and structure of the screen as well as item analyses. They provide evidence of similar and comparable qualities of measurement in the three culturally divergent populations, indicating that the screen is likely to produce comparable data across cultures. One of the questions, however, correlates with the other questions differently in Jamaica, where it appears to "over-identify" children as seriously disabled. The methods and findings reported here have general applications for the design and evaluation of questionnaires for epidemiologic research, particularly when the goal is to gather comparable data in geographically and culturally diverse settings.

Reviewing all the above mentioned research works it is seen that the previous researchers either attempted to find out the causes of retardation or investigated specific syndromes. Practically nothing was done to suggest ways and means those are helpful to rehabilitate the mentally retarded persons in Bangladesh.

The researcher also found that none of the previous researchers studied the housing and social security problems of the mentally retarded persons in Bangladesh. Whereas these two areas, housing and social security are most important concerns of the parents of the adult mentally retarded persons in Bangladesh.

The psychosocial problems of the mentally retarded persons and their family members can be generalized in five broad areas-these are health, education, employment, housing and social security. To formulate a National Policy for the mentally retarded persons in Bangladesh enough information is needed on these five areas. Therefore, the researcher attempted to study the psychosocial co-relates of mental retardation including these five specific areas.

### **Objective of the study:**

The main objective of this research was to study the psychosocial co-relates of mental retardation of some selected cases. This includes their health, education, employment, housing and social security matters. And the specific objectives are:

1. to study the growth and health matters of the cases.
2. to study the impact of special education and vocational training on employment and rehabilitation of the cases.
3. to study the housing problems and prospects of the cases.
4. to study the social security problems of the cases, and
5. to compare the problems and prospects of the rural and urban mentally retarded persons in Bangladesh.

### **Significance of the study:**

It is assumed that the findings will help facilitate formulation of a National Policy for the mentally retarded persons in Bangladesh. If a National Policy is announced in the country, obviously, the Government will undertake some programs. If a National policy is announced the NGOs will not be able to do trials and errors with the mentally retarded persons and their families.

The findings will be helpful for the future researchers, medical doctors, special education teachers and all other concerned professionals.

# *Chapter-II*

## *Method*



# Chapter II

## Method

This study, the psycho-social correlates of mental retardation is mainly the case studies of some of the mentally retarded persons in Bangladesh. In this study a specially designed questionnaire was used. The respondents of this questionnaire were mainly the parents/guardians of the mentally retarded persons. The researcher also studied each case by herself at special schools and at their residence.

### **Materials used:**

This research which is mainly the case studies was done with the help of a Questionnaire. There was one set of questions for the parents/guardians, divided into two parts. The first part was Information blank to collect primary information about the mentally retarded persons and their parents. And the other part of the Questionnaire was to assess different problems and prospects of the mentally retarded persons. The questionnaire had five sections related to Health, Education, Employment, Social Security and Housing of the subjects. There were about 60 questions related to the problems and prospects of the mentally retarded persons.

The researcher with the help of her research supervisor developed the Questionnaire in 1999 at Rajshahi University Psychology Department. The main bases of item selection of the questionnaire were the following:

- Normal development pattern of human beings as described in the books of Developmental Psychology.
- Observation of different behavioral aspects of the mentally retarded children by the researcher herself during 1991-1998 in Rajshahi City and in some of the adjoining areas.
- Open informal interviews with about 30 parents/guardians/teachers of the mentally retarded children of Rajshahi City and the adjoining areas.

- Discussion with some general physicians, psychologists, psychiatrists, special education teachers, counselors, welfare staff, etc. who worked with the mentally retarded persons for several years.

The first part included items like, name of the persons, addresses, age, father's name, mother's name, educational level of the fathers and the mothers, source of income of the father, ownership of residence, number of siblings, etc. And the other part of the questionnaire is designed to obtain various kinds of information about the mentally retarded persons. There are five different areas in this questionnaire related to health, education, employment, social security and housing of the subjects as mentioned below:

### **Health:**

There are 18 questions in this section related to health matters of the subjects. The contents of this section also included health related information of the fathers of the subjects. This information included-diseases suffered by the fathers from their own infancy till birth of the mentally retarded child, performance levels of their own sensory systems, treatments, immunisation, etc.

Detail information about the mothers (all information like the fathers as mentioned above). In addition, the mothers gave information about their all pregnancies and abortions in a special table.

Detail information about the prenatal period, perinatal period and postnatal period of the mentally retarded child.

Detail information about the diseases and illnesses of the mentally retarded children, their developmental characteristics, behavioural problems, treatments, etc.

### **Education:**

This section has 14 questions, which are related to the educational programs of the mentally retarded persons. The contents of this section are mentioned below:

Detail information of the past and present educational status of the mentally retarded persons, Schooling, special educational program of the mentally retarded persons, behaviour with teachers and peers, improvement due to the schooling, etc.

### **Employment:**

There are 10 questions in this section related to the employment condition of the mentally retarded persons. The contents of this section are mentioned below.

Detail information about employment quota system, supportive employment services, sheltered workshop services, monthly salary system of the mentally retarded persons, etc.

Vocational training or any other special training related questions were also included in this section to assess their self-sufficiency and independent status in adult life.

Questions related to unemployment allowance for the persons with severe mental retardation were also added in this section.

### **Housing:**

There are 10 questions in this section related to housing problems and socio-economic status of the mentally retarded persons. The contents of this section are mentioned below:

The questions included were designed to know the number of family member of the mentally retarded persons.

Detail information about housing status, food, room, and clothes of the mentally retarded persons.

Detail information about behaviour at home, with siblings, with unknown people, known people of the mentally retarded persons. The questions about marriages of the mentally retarded persons, future plan of the parents related to marriage of the mentally retarded persons.

**Social security:**

This section has 10 questions related to social security of the mentally retarded persons. Questions related to pension schemes, old age home, institution for the aged mentally retarded persons, government benefit for the mentally retarded persons, protection of their personal well-being and property, protection from exploitation, abuse, insurance scheme etc. were included.

**Psycho-social factors:**

Different sections of the case study form also contained questions regarding some psycho-social factors that are supposed to be causally related to mental retardation in Bangladesh. The case study form covered mainly the following psycho-social factors:

**Psychological factors:** Anxiety of the pregnant mothers, mental shock of the pregnant mothers, family trouble during pregnancy, beliefs and values of the parents, etc.

**Social factors:** Education, employment, social security, housing, religion, income, places of living, etc.

**Development of the Questionnaire:**

The first draft of the questionnaire was applied on the parents and guardians of 30 mentally retarded persons. The researcher also interviewed the parents and the guardians at the time of their filling up of the questionnaire. The questionnaire was then revised by the researcher on the basis of her own observation and the answers given by the parents / guardians. This revised questionnaire was then again applied on the same sample and it appeared to work satisfactorily.

The revised draft was also reviewed by a group of psychologists, sociologists, psychiatrists and general physicians working in different programs for the mentally retarded persons. A final revision of the questionnaire was made on the basis of comments given by the experts mentioned above. The final questionnaire was then printed.

One important section of the Questionnaire is the Checklist to assess the level of handicapped condition of the subjects. As it is practically impossible to administer any standard Intelligence test on the mentally retarded persons, the research supervisor for his own Doctoral research originally developed the checklist section of the questionnaire. The checklist was used to study about 800 mentally retarded children and adults during 1988-1992 at different places of the country. The panel of experts made little amendment of the original checklist. Then another researcher of Rajshahi University Institute of Bangladesh Studies, Dr. M Anisuzzaman (2000) used the same checklist to study about 142 mentally retarded adults. The main focus of administering this checklist was to study the behavioural and social aspects of the mentally retarded persons.

There are many items in the contents of this checklist. This checklist was designed as a five-point scale to assess five performance levels such as, "very good", "good", "average", "poor" and "very poor". Scoring of the checklist involves assigning a numerical value of 5, 4, 3, 2 and 1 respectively to each response. The researcher read each item of the checklist and the guardians gave their opinion. In the present study the guardians responded on the basis of their own observation and rated the mentally retarded person's behavioural levels. The items included are related to sensory levels, eating, dressing, walking, playing, social interactions, education, aggression, emotion, memory, personality, motivation, etc. of the mentally retarded persons.

The Bengali version of the questionnaire and its English translation are shown in Appendices I and II respectively at the end of this thesis.

### **Sample and the subjects:**

This research is detail case studies of 247 (144 Urban and 103 Rural) mentally retarded persons living in different urban and rural places in Bangladesh. The researcher personally observed and studied all the 247 mentally retarded subjects. Formal case studies were done mainly during 2001 and 2003. However, the researcher, from 1992 to 2003 longitudinally studied some specific cases living in Rajshahi city.

Out of these 247 subjects, 103 are rural subjects (72 were males and 31 were females) and 144 are urban subjects (93 were males and 51 were females) as shown in Table 2.3. Detail age-wise distributions of the subjects are shown in Table 2.4.

Degree of retardation of the subjects of this study are shown in Figure-2.1.

The mentally retarded subjects living with parents and other relatives in different categories of families are shown in the Figure-2.4.

Mainly the parents/guardians of the mentally retarded subjects were the respondents in this study. Though major respondents of this study were the fathers and the mothers, in some cases the siblings or other relatives acted as the major respondents in the absence of the parents. Details of the respondents are shown in Table 2.2.

**Table-2.1:** District wise distribution of the mentally retarded subjects

Districts	Urban		Rural	
	N	%	N	%
Dhaka	56	38.89	0	0.00
Gazipur	0	0.00	13	12.62
Rajshahi	79	54.86	78	75.73
Naogaon	0	0.00	12	11.65
Bogra	9	6.25	0	0.00
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

**Table-2.2:** Major Respondents of the Study

Major Respondents	Urban		Rural	
	N	%	N	%
Father	33	22.92	32	31.07
Mother	99	68.75	53	51.46
Siblings	9	6.25	4	3.88
Other relatives	3	2.08	14	13.59
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

When the researcher went to the Mentally Retarded persons for collecting information about them, in some cases the mothers and in some cases the fathers provided information. Sometimes both the father and the mother jointly gave the information. The persons who gave maximum information were considered as the respondents. But sometimes, the father was not at home. In such cases, the information has been taken from the mother. In the absence of the parents, sometimes, siblings and sometimes other relatives gave information. In the rural cases, 31.07% respondents are fathers, 51.46% respondents are mothers, 3.88% are siblings and 13.59% are some other relatives. On the other hand in the urban cases, 22.92% respondents are fathers, 68.75% respondents are mothers, 6.25% are siblings and 2.08% are some other relatives. From the above table, it is seen that maximum numbers of the respondents are the mothers.

**Table-2.3:** Sex of the mentally retarded person

Sex	Urban		Rural	
	N	%	N	%
Male	93	64.58	72	69.90
Female	51	35.42	31	30.10
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

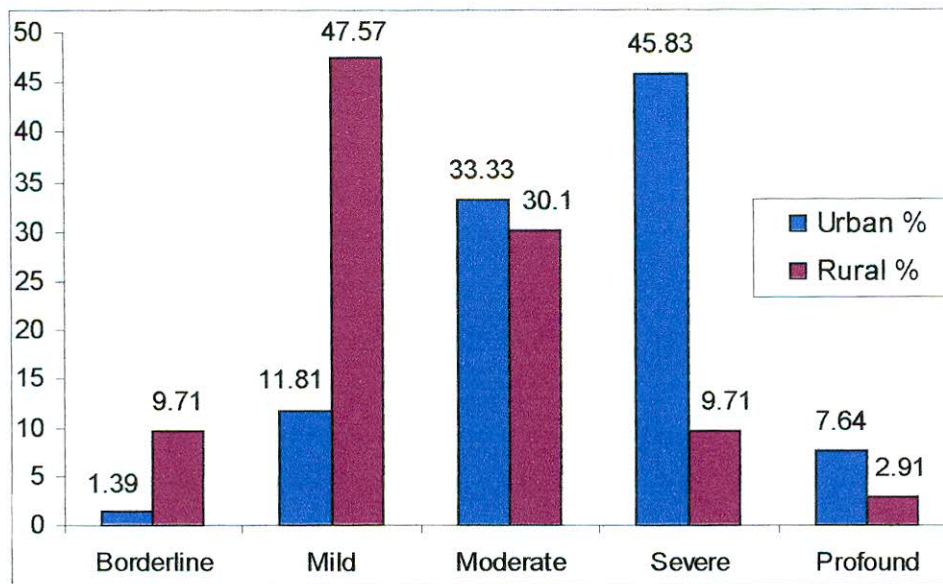
The total number of the Rural Mentally Retarded persons is 103. Of them, the male Mentally Retarded persons are 72, (69.90%) and the female Mentally Retarded persons are 31, (30.10%) on the other hand the total number of the Urban Mentally Retarded persons is 144. Of them, the male Mentally Retarded persons are 93, (64.58%) and the female Mentally Retarded persons are 51, (35.42%). Surprisingly the number of male Mentally Retarded persons was found nearly double than that of the female mentally retarded persons in both the rural and urban areas. But it is not projecting the real situation of the country. It is assumed that the prevalence of male and female subjects are similar. The researcher obtained list of the mentally retarded persons from concerned NGOs. It is assumed that female subjects are relatively lesser in numbers who are affiliated with such NGOs. Secondly, there are scarcities of information and data with the Bureau of Statistics in Bangladesh.



**Table-2.4:** Age range of the mentally retarded person

Age range in years	Urban		Rural	
	N	%	N	%
0-5	17	11.81	11	10.67
6-10	52	36.11	31	30.10
11-15	57	39.58	29	28.16
16-20	6	4.17	13	12.62
21-25	5	3.47	7	6.80
26-30	5	3.47	7	6.80
30+	2	1.39	5	4.85
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

The total numbers of the mentally retarded persons were divided into different age ranges as shown in the above table. In the rural and urban areas it is seen that the number of mentally retarded persons in 0-5 years age range is only 10.67% and 11.81% respectively. This number is much lesser than 6-10 years age range. Maybe, it was not possible to identify all the mentally retarded persons in 0-5 years age range. Following the 6-15 years age range, the number is increased and 16-30 years age range, the number is sharply declined. It is seen in the table above that the number of the rural and urban mentally retarded persons above 30 years is only 4.85% and 1.39% respectively. Therefore, it can be said that the mentally retarded persons do not live longer in Bangladesh.

**Figure-2.1:** Degree of retardation of the subjects

The number and percentage of the Mentally Retarded persons according to their degree of retardation is presented in the above figure. It is seen that in the rural areas the Borderline Mentally Retarded persons are only 9.71%; Mild 47.57%; Moderate 30.10%; Severe 9.71%; and Profound 2.91%. The trend is not similar in urban areas. It is also seen that the number of severe and profound Mentally Retarded persons is lesser in rural areas than the number of Mild Mentally Retarded persons.

**Table -2.5:** Present Age of the fathers of the mentally retarded person

Age range (in years)	Urban		Rural	
	N	%	N	%
20 – 25	2	1.39	5	4.85
26 – 30	21	14.59	8	7.77
31 – 35	17	11.81	12	11.65
36 – 40	34	23.61	21	20.39
41 – 45	22	15.26	15	14.56
46 – 50	17	11.81	11	10.68
51 – 55	9	6.25	8	7.77
56 – 60	7	4.86	7	6.80
60+	15	10.42	16	15.53
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

In the above table the present age of the fathers of the Mentally Retarded persons divided into different age group has been presented.

**Table -2.6:** Profession of the fathers of the mentally retarded person

Main Profession	Urban		Rural	
	N	%	N	%
Service	76	52.78	6	5.82
Agriculture source or income from lands buildings, other assets, etc.	16	11.11	76	73.79
Business	48	33.33	10	9.71
Others	4	2.78	11	10.68
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

Main professions of the fathers of the Mentally Retarded persons are shown in the above table. In the rural areas it was found that Service is only 5.82%, Agriculture is 73.79%, Business is 9.71% and others 10.68%. It is seen that the occupation of most of the fathers of the Mentally Retarded persons in rural areas is agriculture.

On the other hand in the urban areas the percentage is as follows, Service is 52.78%, Agriculture is 11.11%, Business is 33.33% and others 2.78%. It is seen that the occupation of most of the fathers of the Mentally Retarded persons in urban areas is service.

From the above findings it is clearly understood that there are differences in the professions of rural and urban parents in Bangladesh.

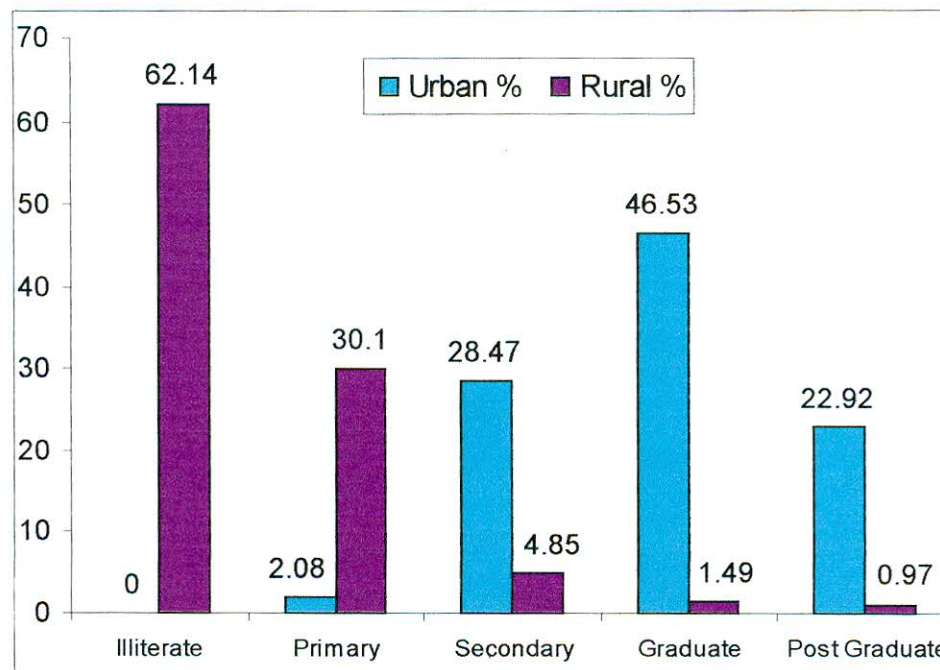
**Table -2.7:** Yearly income of the fathers of the mentally retarded person

Yearly income (in thousand Taka)	Urban		Rural	
	N	%	N	%
00 – 10	0	0	19	18.45
11 – 20	0	0	33	32.04
21 – 30	3	2.09	27	26.21
31 – 40	11	7.64	12	11.65
41 – 50	17	11.81	9	8.74
51– 60	26	18.06	2	1.94
60 +	87	60.40	1	0.97
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

Yearly income of the fathers of the Mentally Retarded persons is shown in the above table. The researcher assessed the amount of this income through consultation with them.

The researcher noticed that the income of the fathers is very low in the rural areas.

**Figure-2.2:** Educational qualification of the fathers of the mentally retarded person



In the above figure, the educational qualification of the fathers of the Mentally Retarded persons has been shown.

It is seen that in the rural areas most of the fathers are illiterate. Only 30.10% passed primary schools and the number of graduates and postgraduates are very low.

On the other hand in the urban areas none of the fathers are illiterate. Only 2.08% passed primary schools and the number of graduates is very high (46.53%).

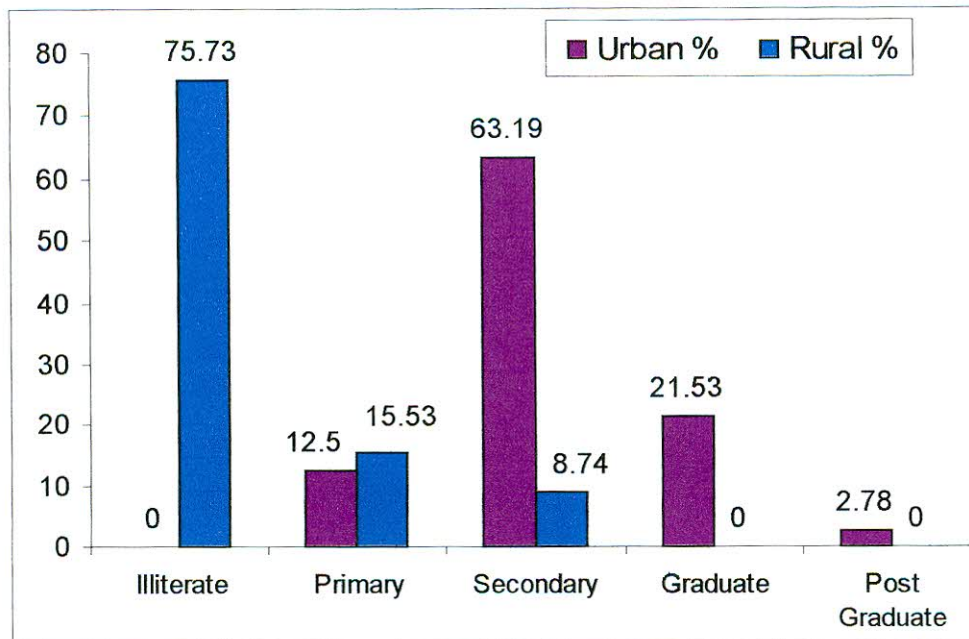
**Table -2.8:** The present age of the mothers of the mentally retarded person

Age range (in years)	Urban		Rural	
	N	%	N	%
16 – 20	0	0	3	2.91
21 – 25	4	2.78	7	6.80
26 – 30	27	18.75	17	16.50
31 – 35	12	8.33	19	18.45
36 – 40	12	8.33	23	22.33
41 – 45	31	21.53	13	12.62
46 – 50	28	19.44	10	9.71
51 – 55	21	14.59	3	2.91
55 +	9	6.25	8	7.77
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

The present ages of the mothers of the Mentally Retarded persons divided in nine age ranges are shown in the above table.

It is seen that in the rural areas, the number of the mothers in the age range 36-40 years is 22.33% and there are 2.91% mothers in the age range 16-20 years.

On the other hand it is seen that in the urban areas the picture is different. None of the urban mothers were found in the age range 16-20 years. Large majorities of the urban mothers are aged over 21 years.

**Figure-2.3:** Educational qualification of the mothers of the subjects

The details of the educational qualifications of the mothers of the Mentally Retarded persons have been presented in the above figure.

In the rural areas it was found that 75.73% mothers are illiterate, 15.53% mothers have primary education, 8.74% mothers passed secondary school and there is no mother who is of graduate or post graduate levels.

On the other hand in the urban areas it was found that none of the mothers are illiterate. 63.19% mothers have secondary education.

From these findings it is seen that the educational qualifications of the urban mothers of the Mentally Retarded persons is higher than that of the rural mothers of the Mentally Retarded persons.

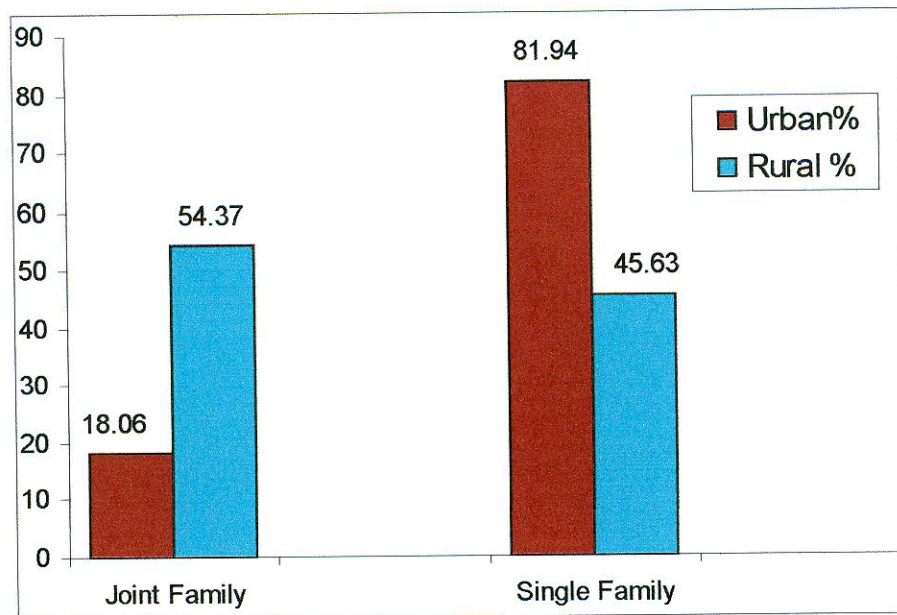
**Table-2.9:** Yearly personal income of the mothers of the mentally retarded persons

Yearly income in Taka	Urban		Rural	
	N	%	N	%
00 – 1000	0	0	52	50.49
1100 – 2000	0	0	17	16.50
2100 – 3000	0	0	15	14.56
3100 – 4000	0	0	8	7.77
4100 – 5000	0	0	6	5.83
5100 – 6000	67	46.53	3	2.91
6100 +	77	53.47	2	1.94
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

The researcher noticed that in the rural areas, the roles of mothers in the economic fields are not considered as important in comparison to fathers. Yet, the income of the family means the income of the father. In some special cases, some types of income referred as mothers' income included rearing poultry, sewing and handicrafts manufacturing, etc.

It was found that among the mothers of urban areas 46.63% earn between 5100-6000 Taka per year. And 53.47% earn more than 6000 Taka per year. The pictures of earning status of mothers of the urban areas are different from the mothers of rural areas.



**Figure-2.4:** Categories of families of the subjects

The family structure of the Mentally Retarded persons with whom they live in at present are shown in the above figure.

In rural areas it is seen that the number of the joint families is 54.37% and the number of the single families is 45.63%.

On the other hand in urban areas it is seen that the number of the joint families is 18.06% and the number of the single families is 81.94%.

**Table-2.10:** Marital prospects of the subjects

Response	Urban		Rural	
	N	%	N	%
Yes	22	22.28	52	50.49
No	98	68.05	16	15.53
Married	21	14.59	12	11.65
No answer	3	2.08	23	22.33
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

All the parents/guardians were asked whether they are thinking arrangement of marriage of their mentally retarded sons and daughters.

In the rural areas it was found that 11.65% of the Mentally Retarded persons are already married. Parents of the remaining mentally retarded persons were asked that whether they would try their children get married. 50.49% said 'Yes' and 15.53% said 'No'. 22.33% of the parents did not make any comment. It is seen that most parents are willing to arrange marriage of their children.

On the other hand in urban areas it was found that 14.59% of the Mentally Retarded persons are married. Parents of the remaining mentally retarded persons were asked that whether they would try their children get married. 22.28% said 'Yes' and 68.05% said 'No'. 2.08% of the parents did not make any comment. The attitudes of the parents were found different in rural and urban areas.

**Table-2.11: Age of the father at birth of the mentally retarded child**

Age Range (In years)	Urban		Rural	
	N	%	N	%
18 – 20	2	1.39	9	8.73
21 – 25	9	6.25	31	30.10
26 – 30	36	25.00	23	22.33
31 – 35	44	30.55	11	10.68
36 – 40	35	24.31	6	5.83
40+	18	12.50	23	22.33
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

The age of the fathers at the time of birth of the Mentally Retarded children have been presented in the above table.

It is seen that in the rural areas, 8.73% fathers were in 18-20 years age range; 30.10% were in 21-25 years age range; 22.33% were in 26-30 years age range; 10.68% are in 31-35 years age range; 5.83% were in 36-40 years age range and 22.33% were in 40+ age range. The number of the fathers in 40+ age range is relatively higher in the rural areas.

On the other hand it is seen that in the urban areas, 1.39% fathers were in 18-20 years age range; 6.25% were in 21-25 years age range; 25.00% were in 26-30 years age range; 30.55% are in 31-35 years age range; 24.31% were in 36-40 years age range and 12.50% were in 40+ age range. It is found that in the urban areas the number of the fathers in 31-35 age range is relatively higher.

**Table-2.12:** Age of the mother at birth of the mentally retarded child

Age Range (In years)	Urban		Rural	
	N	%	N	%
15 – 20	1	.69	42	40.78
21 – 25	8	5.56	26	25.24
26 – 30	53	36.81	16	15.53
31 – 35	67	46.53	9	8.74
36 – 40	11	7.64	8	7.77
40 +	4	2.77	2	1.94
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

Mothers' ages at the time of birth of the Mentally Retarded children have been presented in the above table.

It is seen that in the rural areas, the number of the mothers aged from 15 to 25 years is the largest group. Gradually this rate has declined. On the other hand in the urban areas, the number of the mothers aged from 31-35 years is the largest group.

It is seen that in the rural areas, 40.78% mothers were in 15-20 years age range at the time of birth of the mentally retarded children; 25.24% mothers were in 21-25 years age range; 15.53% mothers were in 26-30 years age range; 8.74% mothers were in 31-35 years age range; 7.77% mothers were in 36-40 years age range; and 1.94% mothers were in 40+ years.

Whereas, it is seen that in the urban areas, 0.69% mothers were in 15-20 years age range at the time of birth of the mentally retarded children; 5.56% mothers were in 21-25 years age range; 36.81% mothers were in 26-30 years age range; 46.53% mothers were in 31-35 years age range; 7.64% mothers were in 36-40 years age range; and 2.77% mothers were in 40+years.

Therefore, it can be said that in the rural areas, a large number of the cases, immature mothers gave birth of the Mentally Retarded children. On the other hand, in the urban areas, it is found that most of the cases, aged mothers gave birth of the Mentally Retarded children.

**Table-2.13: Marriage among close relations**

Close-relation	Urban		Rural	
	N	%	N	%
Yes	26	18.06	27	26.21
No	118	81.94	76	73.79
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

Marriage among close relations (mainly among cousins) between a father and a mother is shown in the above table.

It is seen that in the rural areas, 26.21% fathers and mothers were close relations and in the urban areas, 18.06% fathers and mothers were close relations. However, it was found that in most of the cases, the parents were not close relations both in the urban and the rural areas.

**Methods of Research:**

The researcher mainly followed case study and interview method to collect primary data. In addition, Observation and Free discussions were extensively done during the case studies. The researcher also observed all the subjects in different social conditions. She had free and informal discussions with the parents/ guardians in relation to behaviour problems and prospects of the subjects, too.

**Case Studies:**

Case study refers to the collection and presentation of detailed information about a particular participant or small group, frequently including the accounts of subjects themselves. A form of qualitative descriptive research, the case study looks intensely at an individual or small participant pool, drawing conclusions only about that participant or group and only in that specific context. Case studies are frequently discussed within the context of qualitative research and naturalistic inquiry. Case studies are often referred to interchangeably with ethnography, field study, and participant observation. The underlying philosophical assumptions in the case are similar to these types of qualitative research because each takes place in a natural setting (such as a classroom, neighborhood, or private home), and strives for a more holistic interpretation of the event or situation under study.

Unlike more statistically based studies, which search for quantifiable data, the goal of a case study is to offer new variables and questions for further research. F.H. Giddings, a sociologist in the early part of the century, compares statistical methods to the case study "on the basis that the former are concerned with the distribution of a particular trait, or a small number of traits, in a population, whereas the case study is concerned with the whole variety of traits to be found in a particular instance" (Hammersley, 1995).

Case studies emphasize detailed contextual analysis of a limited number of events or conditions and their relationships. Researchers have used the case study research method for many years across a variety of disciplines. Social scientists, in particular, have made wide use of this qualitative research method to examine contemporary real-life situations and provide the basis for the application of ideas and extension of

methods. Researcher Robert K. Yin defines the case study research method as an empirical inquiry that investigates a contemporary phenomenon within its real life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used (Yin, 1984).

Case studies can be single or multiple-case designs, where a multiple design must follow a replication rather than sampling logic. When no other cases are available for replication, the researcher is limited to single-case designs. Yin (1994) pointed out that generalization of results, from either single or multiple designs, is made to theory and not to populations. Multiple cases strengthen the results by replicating the pattern-matching, thus increasing confidence in the robustness of the theory. Applications of case study methodology have been carried out in High-Risk Youth Programs (Yin, 1993) by several researchers.

The effects of community-based prevention programs have been widely investigated using case methodology. Where the high risk youth studies assumed a single case evaluation, these studies have typically used a collection of cases as a multiple-case study. This has been true in the various substance abuse prevention programs that are community-based (Holder, 1987; Sabol, 1990; Yin, 1993). Numerous such studies sponsored by the U. S. General Accounting Office are distributed in the literature between Evans (1976) and Gopelrud (1989). These studies have gone beyond the quantitative statistical results and explained the conditions through the perspective of the "actors." Thus case study evaluations can cover both process and outcomes, because they can include both quantitative and qualitative data.

There are several examples of the use of case methodology in the literature. Yin (1993) listed several examples along with the appropriate research design in each case. There were suggestions for a general approach to designing case studies, and also recommendations for *exploratory*, *explanatory*, and *descriptive* case studies. Each of those three approaches can be single or multiple-case studies, where multiple-case studies are replicatory, and not sampled cases. There were also specific examples in education, and management information systems. Education has embraced the case method for instructional use. Some of the applications are reviewed in this paper.

In *exploratory* case studies, fieldwork, and data collection may be undertaken prior to definition of the research questions and hypotheses. This type of study has been considered as a prelude to some social research. However, the framework of the study must be created ahead of time. Pilot projects are very useful in determining the final protocols that will be used. Survey questions may be dropped or added based on the outcome of the pilot study. Selecting cases is a difficult process, but the literature provides guidance in this area (Yin, 1989a). Stake (1995) recommended that the selection offers the opportunity to maximize what can be learned, knowing that time is limited. Hence the cases that are selected should be easy and willing subjects. A good instrumental case does not have to defend its typicality.

*Explanatory* cases are suitable for doing causal studies. In very complex and multivariate cases, the analysis can make use of pattern-matching techniques. Yin and Moore (1987) conducted a study to examine the reason why some research findings get into practical use. They used a funded research project as the unit of analysis, where the topic was constant but the project varied. The utilization outcomes were explained by three rival theories: a knowledge-driven theory, a problem-solving theory, and a social-interaction theory.

Knowledge-driven theory means that ideas and discoveries from basic research eventually become commercial products. Problem-solving theory follows the same path, but originates not with a researcher, but with an external source identifying a problem. The social-interaction theory claims that researchers and users belong to overlapping professional networks and are in frequent communication.

*Descriptive* cases require that the investigator begin with a descriptive theory, or face the possibility that problems will occur during the project.

A frequent criticism of case study methodology is that its dependence on a single case renders it incapable of providing a generalizing conclusion. Yin (1993) presented Giddens' view that considered case methodology "microscopic" because it "lacked a sufficient number" of cases. Hamel (Hamel *et al.* 1993) and Yin (1984, 1989a, 1989b, 1993, 1994) forcefully argued that the relative size of the sample whether 2, 10, or



100 cases are used, does not transform a multiple case into a macroscopic study. The goal of the study should establish the parameters, and then should be applied to all research. In this way, even a single case could be considered acceptable, provided it met the established objective.

The case study approach to research in the behavioural sciences is the most peculiar method for gaining insight into why an individual acts in a certain way and how he is likely to act in future. The term case study refers to a rather intensive examination of some single unit. The unit, however, is not always restricted to one person. The unit may be a single school, institution, organization, district, group, community, an individual, or even a single event. Sometimes, the case study label is used even when two or three "respective" units or instances are selected and are subjected to an unusually detailed description.

The researcher, who uses this approach, tries to see the individual, his situation, and his behaviour as the total configuration on factors that affect him through time. The case study is a Gestaltist or holistic approach to the understanding of the people rather than an elementaristic means of analysing human behaviour by adding together similar trials and behaviours as is done in the 'survey research' (Thakur, 1998).

There are some advantages and disadvantages in case study method:

#### Advantages:

The case study approach is used in sociology primarily for the insights it can offer to guide further research on large samples. The purpose of the case history is to see how action and attitudes develop over a period of time. It preserves the integrity of the units under study.

Case study adds to our knowledge. It is a tremendous producer of ideas, suggestions and hypotheses about behaviour. It is an essential technique for exploring completely new fields when we do not have any idea of the commonalties or the categories of variables, which play important part in a situation. Also when we are trying to formulate new concepts or a new framework within which to carry out controlled experiments later on then the case study method is highly productive.

**Disadvantages:**

This method depends upon the recall of others experiences or knowledge regarding past events. This delimits the effectiveness of the method. The information collected through case studies is not sufficient for making meaning generalization, concerning larger social aggregates. The researcher can obtain incomplete data. Case studies are more time consuming than surveys (Thakur, 1998).

Though the researcher mainly followed the Case Study method, to complete the case studies, the researcher had to follow some other sub methods, such as, Observation, Question and answer, and Free Discussion.

**Observation:**

As in all other sciences, the bedrock, of psychological knowledge is observation, and what psychologists observe is the behaviour of organisms. The focus of such observation is variable and includes the overt actions of an organism, certain of its measurable internal behaviours (*e.g.* its physiological processes), and at the human level verbal reports about inner processes or events. It is by far the most troublesome and yet often the most interesting and potentially useful. Of course, all of us observe our own overt behaviour and certain of our inner events, such as thoughts and feelings. But self- observation of one's inner processes has distinct limits as a database for psychological science, in part because much important mental activity is carried on automatically, so to speak, outside of the range of a person's awareness (Nisbett and Wilson, 1977). In addition, mental events are in their fundamental nature private events, forever inaccessible to confirmation by anyone else. Science normally demands such confirmation (inter subjective reliability) by others as a means of assuring accuracy in the observations made. This constraint has been a source of considerable difficulty for the discipline of psychology throughout its history.

Scientific observational methods employ systematic techniques by which observers are trained to watch and record behaviour without bias. Such methods have helped to ensure the scientific integrity of observational research, but obstacles still remain. (Carson *et al.* 1996).

**Behavioural Observation:** Direct behavioural observations should be considered a primary method of evaluating particular critical responses in the mentally retarded child's repertoire. It is generally believed by behaviour therapists that nothing substitutes for behavioural observations because they can be used to pinpoint target behaviours and to identify antecedent and consequent events that may influence the occurrence or non-occurrence of specific responses (Matson and Beck, 1981).

The major strength of behavioural observations is that they entail direct observation and recording of responses as they occur naturally in everyday settings. Moreover, direct observations are often continuous over a period of time and, thus, can provide a larger sample of behaviour than assessments that occur during limited and perhaps contrived therapy sessions or environmental contexts. For example, if a child's interaction with peers on the playground is a problem area, then that child can be observed directly in that setting for several days. Responses that can be recorded include the duration of time the child can successfully interact with others, the number and characteristics of peers, teacher reactions to responses, the specific activities engaged in, and the frequency and intensity of undesired behaviour such as physical outbursts. Gottlieb (1978) stresses the interactive nature of behaviour in the examination of the mentally retarded child's social adaptation to school; hence, the child's observable behaviour is expressed within a context of peer and teacher characteristics and responses. An unanswered question is the degree to which the mentally retarded child's behaviour is similar across settings and in the responses it elicits from other persons (Gottlieb, 1978).

Comprehensive behavioural observations in school include attention to academic responding. For example, the frequency, accuracy, and duration of oral and written responses in the various content areas can be measured in order to gain an understanding of the child's daily academic functioning. Knowledge of a child's actual performance in the curriculum used in his/ her school is likely to be more revealing than a score on a standardized achievement test. For instance, an observational analysis of a child's math skills may show a greater proficiency in math facts when the response mode is oral than it is written or when certain reinforcement

contingencies are in effect. This type of information is especially helpful to the classroom teacher, as it carries programmatic implications. In the case of the math example, then, the child who has difficulty writing numbers can more efficiently memorize math facts through the use of flashcards. Instruction in writing skills can proceed in a way that does not confound with other skills (Bornstein and Kazdin, 1985).

In this research observation method was used to study the psycho-social aspects, problems and prospects of the mentally retarded cases. The parents, guardians and the family members reported the psycho-social aspects to the researcher on the basis of their observation. The researcher herself also studied the behaviour of the subjects. In most cases she had free access to the home to observe the mentally retarded persons during informal situations. The researcher spent times during classes or leisure inside the special classes with the permission of the teachers in the urban areas. The researcher also visited most of the houses of the mentally retarded persons to observe them while they are engaged in different household activities. The researcher also observed different psycho-social items of the case study form and the checklist.

### **Question and Answer:**

The researcher asked the questions to the family members according to the sequence of the questions in the case study form. There were both Yes/ No answers and detail answers. The family members narrated detail behaviour of the subjects what they have observed or perceived for many years. The researcher had the questionnaire with her during interviews with the family members. In most cases the sessions started with casual discussions then centred on the mentally retarded family member, then specifically related to psychosocial aspects of the subjects.

### **Free Discussion:**

The family members were given opportunity to narrate anything they liked to talk about their mentally retarded family member. A large number of respondents in this research were the mothers of the mentally retarded persons. Fathers also answered in many cases. When the parents were not available the senior siblings responded. The

free discussion included items related to the liking and disliking of the subjects, their emotions, feelings, thoughts and opinions towards the old age problems of the mentally retarded persons. During free discussions parents and siblings also expressed many of their social problems. It was found that most of the parents were anxious related to the future of their mentally retarded wards. They were found worried about the problem of guardianship of their mentally retarded child after their death. It was also found that most of the urban parents discussed more about the health and treatment matters of the subjects.

## Procedure:

When the questionnaire was ready, the researcher prepared a draft list of about 350 mentally retarded persons affiliated with The SIVUS Institute Rajshahi and SWID (Society for the Intellectually Disabled) Bangladesh. The cases studied in Rajshahi and Naogaon Districts are affiliated with The SIVUS Institute. The cases studied in Rajshahi, Dhaka, Gazipur and Bogra Districts are affiliated with SWID (Society for the Intellectually Disabled) Bangladesh. Some of the students of Rajshahi University Psychology Department, Hatgangopara Degree College and Bandaikhara High School helped the researcher to visit the houses of the mentally retarded persons and their family members in Rajshahi and Naogaon districts. The Special Education Teachers of SWID helped her to study the cases in Rajshahi, Dhaka, Gazipur and Bogra Districts. In the rural areas, the Family Welfare Assistants (FWA), local school teachers, village physicians and the village (Maatbars) leaders helped the researcher to study the cases.

The researcher herself visited the residences of all the cases. In most cases her own students accompanied her from Rajshahi University Psychology Department. When she visited individual cases in the rural areas, the local people, the neighbors of the houses of the subjects were always surrounding her with lot of curiosity. They also observed her assessment and listened what she talked to the parents/guardians. Sometimes they also joined the conversations.

The researcher first used the checklist part of the Questionnaire to assess the level of handicapped condition of the subjects. Then she used the questionnaire. She visited each case on several days. She observed the subjects at home, in fields, in roads, inside neighborhoods and during different interactions. In the urban areas, she observed the subjects at special schools, at their own home and during many social interactions.

During interview with the parents/guardians of the mentally retarded persons, the researcher first observed the mentally retarded subjects, allowed the parents/guardians to express their own feelings about the subjects. All the information given by the parents/guardians in the questionnaire were checked by

the researcher through questioning them again. Most of the parents/guardians mentioned many other things in addition to the selected items of the questionnaire. The researcher recorded all these comments in her notebook.

When the case studies were complete the findings were plotted in a tabulation sheet as well as the data was entered in a personal computer using numerical figures for different responses. Results were determined in terms of percentage. In some cases Chi-square tests were also done.

To come to conclusion and to recommend programs for the mentally retarded persons the researcher considered both the primary and secondary data. Primary data were collected to represent the current situation of the subjects. Therefore, this research combined both secondary and primary data that the objectives of the study can be realised. The researcher also asked the teachers and other professional staff of these two organizations to show the case history files of the subjects. The researcher went through the case history files thoroughly. The researcher also observed the urban subjects at the Day centres for several months in different working situations. The researcher also interviewed the special education teachers, staff members, counsellors, physiotherapists, physicians who seconded the information given by the respondents.

#### **Secondary data:**

The secondary sources of data were the printed and published materials. The statistical reports published by the Government and research bodies, the newspaper articles, etc. These documents were studied by the researcher to obtain the first hand information. The secondary data were processed, classified and tabulated through documentary analysis method for drawing inferences and conclusions. Major sources of secondary data were the following:

- Reports, brochures, souvenirs of some of the related national and international seminars, conferences, etc.
- Statistical reports published by the Bangladesh Bureau of Statistics.
- Reports published by the Government of Bangladesh.

Data published by different associations, such as International Association for the Scientific Study of Intellectual Disabilities (IASSID), American Association on Mental Retardation (AAMR), Asian Federation for the Mentally Retarded (AFMR), Bangladesh National Forum of Organisations Working with the Disabled (NFOWD), The SIVUS Institute, Bangladesh Protibandhi Foundation (BPF), The SWID Bangladesh, etc.

Other secondary data are published books, journals, Internet web sites and unpublished documents like thesis, research monographs, etc.

### **Data Analysis:**

In this study, the researcher plotted data from the responses of the questionnaire. In this study the researcher also plotted data after careful reading of each case history. The researcher both analysed the data manually and through SPSS. The researcher then coded the responses of the questionnaire and behaviour checklist. The researcher opened a file in SPSS (Statistical Package for Social Sciences) 10.0 version. The researcher then defined all the variables in SPSS. Then she completed data entry in SPSS. After completion of data entry the researcher obtained selected statistical analysis. She compared data of the rural and urban cases. She has taken frequencies and cross tabulation in SPSS. She then selected  $\chi^2$  in cross tabulation in SPSS. The researcher used the chi-square test of independence in contingency tables.



*Chapter-III*  
*Results & Interpretations*

# Chapter III

## Results and Interpretation

Researcher used a questionnaire to obtain the primary data. The questionnaire is attached in the Appendices of this thesis. The findings were tabulated mainly into five sections. These five sections are related to Health, Education, Employment, Housing and Social Security. Following section of this chapter includes the findings in different tables.

### **Health:**

To identify the psycho-social correlates of health matters of the mentally retarded subjects and few aspects of their parents, some questions were asked to the parents/guardians of the mentally retarded persons. On the basis of their answers, the following tables were prepared. The bases of interpretations include the primary data, secondary data, observation and interviews.

**Pre-natal Period:****Table -3.1.1:** Pre-natal duration of the subjects

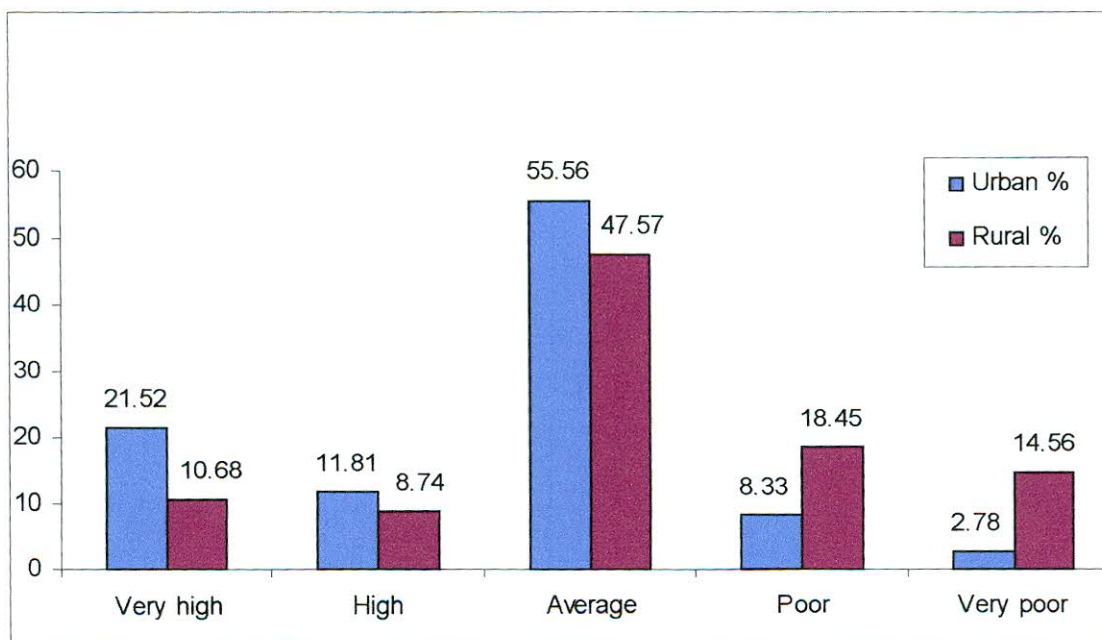
Duration	Urban		Rural	
	N	%	N	%
Full time	108	75.00	67	65.05
Pre-mature	32	22.22	35	33.98
Excess period	4	2.78	1	00.97
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 4.869, df = 2, P < 0.05$$

From the table above it is seen that there are some percentage differences among the rural and urban cases. The large majority of the cases are of full time prenatal duration. The pre-mature cases (urban 22.22% and rural 33.98%) were prone to mentally retarded condition if not provided with proper perinatal and postnatal medical care.

During close interview with the mothers of the subjects, the researcher came to know that many mothers, mainly those with low education could not assess that they conceived. The nature of this unawareness is not dependent on their rural urban living condition. Rather ill health, chronic malnourishment, irregular menstrual cycle and poor health knowledge, etc. are the factors. Therefore, the answers given by the mothers about full time, pre-mature, or excess prenatal period are of questions to the researcher. However, the findings shown in the table above are based on the basis of repeated questions, cross examinations, etc.

The researcher also found that those who mentioned excess period had some delivery problems and birth hazards in the absence of appropriate maternity medical care.

**Figure No. 3.1.1:** Standard of diet of the pregnant mothers

$$\chi^2 = 5.425, df = 4, NS$$

All the mothers were requested to evaluate the overall diet they had during pregnancy period of the subjects. They rated the diet as of very high, high, average, poor and of very poor standard. The number and percentage are shown in the figure above.

It is seen that some differences exist in the self ratings of the rural and urban mothers about their diet during pregnancy period. But these ratings do not tell us whether the diet was a balanced diet or not. Majority of the urban mothers reported average or above average diet. On the other hand majority of the rural mothers reported average and below average diet. However, the large majority of the pregnant mothers had average, poor and very poor diet. These mothers were prone to malnourishment of their own and the fetus. Malnourishment is a significant factor for mentally retarded condition of the babies. In addition, because of the poor diet, the mothers also could not gain sufficient strength for spontaneous delivery and they were subjects of many other complications.

**Table-3.1.2:** Serious illnesses of the mothers during pregnancy period of the subjects

Serious illnesses of the mother during pregnancy period are always a risk for the fetus. The virus of the disease and the chemicals taken as medicine, both can affect the mental development of the baby.

All the mothers were asked whether they suffered any serious illness during pregnancy period of the subjects. They first answered as Yes or No. The following table shows the number and percentage of the given answers.

Response	Urban		Rural	
	N	%	N	%
Yes	14	9.72	12	11.65
No	130	90.28	91	88.35
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 0.237, df = 1, NS$$

Those who said Yes, were asked to mention the diseases. It was found that they mainly had high fever, jaundice, diarrhoea, etc. Those who mentioned only high fever could not inform why they had high fever. It was also found that all of them took some medicine, including antibiotics, during such illnesses.

The chi-square value is not significant and from the above findings it is seen that the rural urban differences are not wide. Also the large majorities of the mothers did not suffer in serious illnesses during pregnancy. Hence this factor is not considered as a statistically significant factor of mental retardation of the subjects.

**Table-3.1.3:** Severe mental anxiety of the mother during pregnancy period of the subjects

Anxiety is a chronic complex emotional state with apprehension or dread as its most prominent component; characteristic of various nervous and mental disorders. It is assumed that the Psychological condition of the pregnant mothers under severe anxiety definitely jeopardize the healthy development of the fetus leading to mental handicap conditions. All the mothers were asked whether they had chronic and severe anxiety during prenatal period of the subjects. They answered as Yes or No.

Response	Urban		Rural	
	N	%	N	%
Yes	120	88.33	54	52.43
No	24	16.67	49	47.57
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 27.55, df = 1, P < 0.01$$

It is seen in above table that 88.33% urban mother had severe mental anxiety during pregnancy period of the mentally retarded child. This rate is lesser among the rural mothers. Whereas 16.67% urban mothers said that they did not have severe anxieties. On the other hand in rural areas 52.43% mother had severe mental anxiety during pregnancy period of the mentally retarded child and 47.57% said that they did not have severe anxieties.

The chi-square test of independence in contingency table is highly significant. It is interpreted that majority of the mothers of the mentally retarded children had severe mental anxiety during pregnancy period of these children which seems to be a related factor for mental retardation of the children. And compared to the rural mothers, the urban mothers had more anxieties.

**Table-3.1.4:** Health check-ups during pregnancy period

Response	Urban		Rural	
	N	%	N	%
Yes	120	83.33	5	4.85
No	24	16.67	98	95.15
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=148, df=1, P < 0.01$$

All the mothers were asked whether they performed regular health check-ups during pregnancy period of the mentally retarded subjects. The mothers responded as 'Yes' or 'No' as answers.

The findings also project the attitude of the mothers towards utilization of modern medical facilities. It is seen that 83.33% of the mothers have done regular medical check-up in urban areas. Among the rural mothers only 4.85% have done the check-up.

Since the chi-square is highly significant at 0.01 level of significance, it can be said that there is a relation between rural-urban living condition and rate of physical check-ups.

**Perinatal period:**

Shortly before birth, the fetus usually rotates into a head- downward position. The movement is referred to as lightening, since it releases pressure on the mother's abdomen. With each uterine contraction the mother experiences considerable pain.

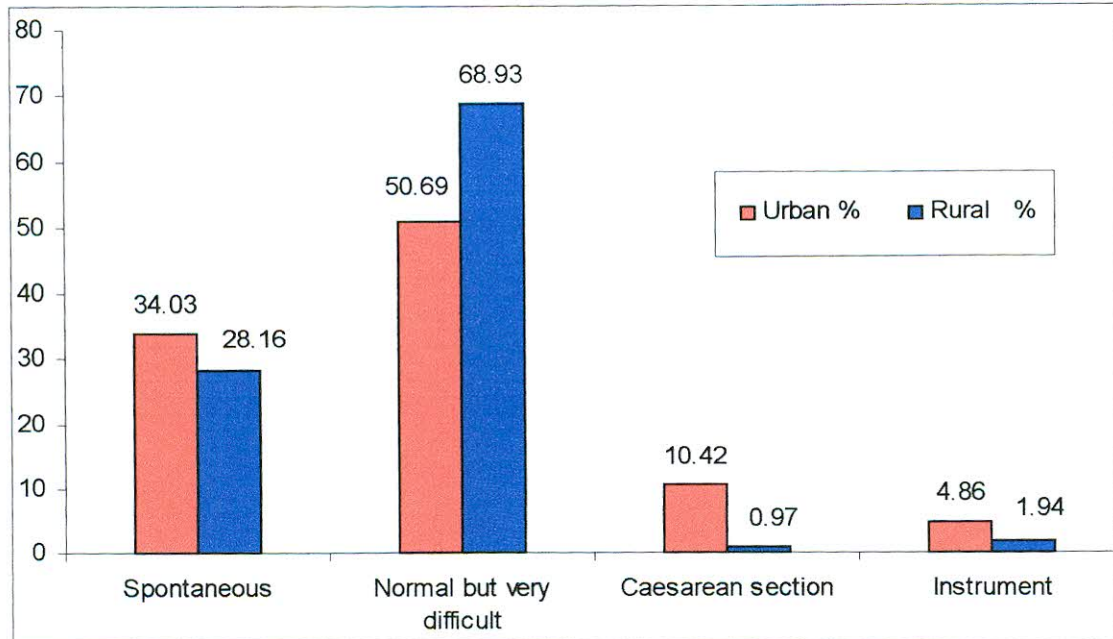
**Table-3.1.5:** Duration of labour pain

Duration	Urban		Rural	
	N	%	N	%
Excessive Prolonged	16	11.11	6	5.83
Prolonged	39	27.08	19	18.45
Long	72	50.00	15	14.56
Short	8	05.56	59	57.28
No pain	9	06.25	4	3.88
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 25.2, \text{ df} = 4, \text{ P} < 0.01$$

In the above table it is seen that 11.11% urban and 5.83% rural cases were born after excessively prolonged pains. These mothers informed that the pain continued for more than two days. Those reported prolonged pains are of one to two days duration. Long cases are maximum of 14 hours and the short cases are of two to six hours duration. Those who had no pain are of surgical sections. Though not the large majority, prolonged labour pain is considered as a significant cause for the birth of mentally retarded children in this country.



**Figure-3.1.2:** Types of birth process of the subjects

$$\chi^2 = 12.35, df = 3, P < 0.01$$

The figure above projects a comparison of birth processes of the subjects in rural and urban areas. It was found that caesarean and instrumental births are low both in urban and rural areas compared to spontaneous and difficult births. It is also seen that only 0.97% subjects in rural areas were born by caesarean sections and 1.94% with the help of instruments.

During interview the researcher came to know that all these cases faced severe problems during births. When the rural midwives failed, the mothers were transferred to Upazilla Health Complexes for delivery. The researcher also came to know that the births were difficult births.

**Postnatal period:**

The researcher asked the parents/guardians, about the age of their children when they came to know that the children were retarded.

**Table-3.1.6:** Age of the subjects when their parents came to know that their children are retarded

Age Range (In years)	Urban		Rural	
	N	%	N	%
0 – 2	12	8.33	1	0.97
3 – 5	31	21.53	23	22.33
6 – 8	73	50.69	41	39.81
9 – 11	26	18.06	27	26.21
12 +	2	1.39	11	10.68
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 7.745, df=4, NS$$

In rural areas it was found that 0.97% of the parents/guardians came to know the condition during 0-2 years age of the children; 22.33% during 3-5 years age range; 39.81% during 6-8 years age range; 26.21% during 9-11 years age range and 10.68% understood the problem when their children were over 12 years.

In urban areas it was found that 8.33% of the parents/guardians came to know the condition during 0-2 years age of the children; 21.53% during 3-5 years age range; 50.69% during 6-8 years age range; 18.06% during 9-11 years age range and 1.39% understood the problem when their children were over 12 years.

It was found that large majority of the parents came to know about the condition when the children were between 3 and 8 years. The findings shown in the above table projects that this awareness status of the urban parents are not widely different from rural parents.

**Table-3.1.7(a):** How did the parents come to know that their child is retarded

Most important symptoms	(Multiple answers)			
	Urban N=144		Rural N=117	
	N	%	N	%
Slow Mental Development	61	42.36	55	47.03
Lack of Social Adjustment	78	54.17	74	66.63
Inability to do School Works	101	70.14	63	53.84
Inability to Perceive Problems and Social Situation	67	46.53	75	64.13
Delayed Physical Development	93	64.59	41	35.04
Inability to perform proper things at proper age	71	49.31	81	69.23

$$\chi^2=4.031, df=5 \text{ NS}$$

The most important symptoms which helped the parents/ guardians to know that their child was retarded are shown in the above table.

It is seen that both in the rural and urban areas slow mental development, lack of social adjustment, inability to do school works, inability to perceive problems, Delayed Physical Development and inability to perform proper things at proper age are the most important symptoms of the subjects which helped parents to guess that their children are retarded.

The findings shown in the above table are self explanatory. Chi-square test was done and the findings are not statistically significant. However, it is understood that lack of social adjustment, inability to do school works and inability to perceive problems and social situation are the most important symptoms these helped parents to understand the retarded condition of their children.

**Table-3.1.7(b):** Persons declared subjects as mentally retarded

Persons	Urban		Rural	
	N	%	N	%
House Physician or General Physician	62	43.06	3	2.91
Qualified Psychiatrists	9	6.25	0	0.00
Psychologists/ Counselor of centers for the mentally retarded	28	19.44	0	0.00
Parent themselves	0	0.00	26	25.24
<b>Pediatrician</b>	43	29.86	2	1.95
Others :( village physician/school teacher)	2	1.39	72	69.90
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=63.24, df=5 \quad P<0.01$$

In the table above it was shown who declared the subjects as mentally retarded. It is seen that there are wide differences in rural and urban areas of the persons who declared them as mentally retarded. During interview the parents said that they first observed the subjects having symptoms mentioned in table 3.1.7(a) and then when they indicated the symptoms to their house physicians (43.06% in the urban cases) only then they took the matter into serious consideration. Mostly the Physicians referred them to Psychiatrists or Psychologists in the urban areas. In rural areas the situation was different. In most of the cases (69.90%) village physician/school teacher declared the child as mentally retarded. The chi-square test of independent in contingency table is highly significant.

**Table- 3.1.8:** Parents facing problems in their family life

Response	Urban		Rural	
	N	%	N	%
Yes, facing problems	88	61.11	56	54.37
No	53	36.81	32	31.07
Can't answer	3	2.08	15	14.56
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=13.88, df=2, P<0.01$$

The parents of the Mentally Retarded persons were asked if there was any problem because of their children's retardation.

In the rural areas, 54.37% parents said 'Yes'; 31.07% parents said 'No'. The reaction of 14.56% parents is not known. On the other hand in the urban areas, 61.11% parents said 'Yes'; 36.81% parents said 'No'. The reaction of 2.08% parents is not known. It is seen that large majority of the families face some problems for the retardation of their children in both the areas.

**Table-3.1.9:** Mother faced problems during pregnancy or at childbirth

Problems	Urban		Rural	
	N	%	N	%
Yes	76	52.78	62	60.19
No	67	46.53	32	31.07
Information Not Available	1	00.69	9	8.74
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=13.77, df=2, P<0.01$$

All the mothers were asked whether they faced any problem during pregnancy or at childbirth. In the rural areas, 60.19% said 'Yes' and 31.07% said 'No'. It was not possible to know the information of 8.74% cases. In the urban areas 52.78% had problems and 46.53% did not have any problem. In urban areas information was not available from 00.69% mothers.

**Table-3.1.10:** Main causes of retardation as viewed by the parents

Causes	Urban		Rural	
	N	%	N	%
Illness of mothers during conception	33	22.92	20	19.42
Infantile diseases of the children	69	47.92	22	21.36
Problems during childbirth	34	23.61	15	14.56
Other reason	5	3.47	24	23.30
Can't answer	3	2.08	22	21.36
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=14.32, df=4, P<0.01$$

When asked about the possible causes of the retardation of their children as viewed by the parents, they mentioned different causes. The assumed causes mentioned by the parents have been presented in the above table.

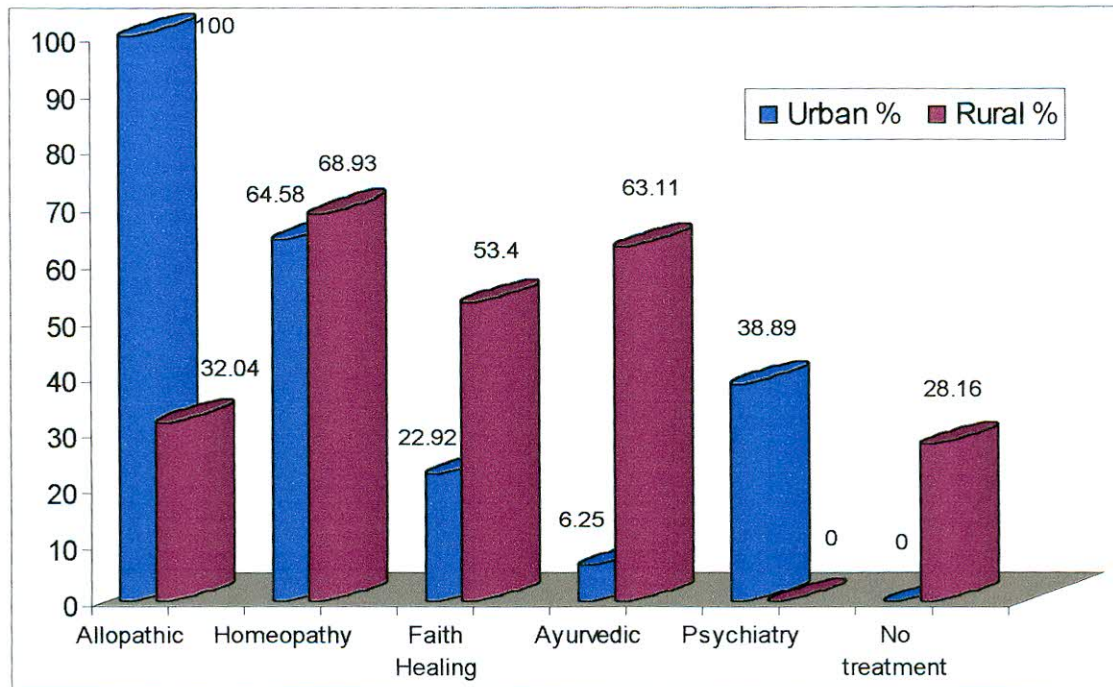
In the rural areas, 19.42% parents think that the causes of retardation are illness of mothers during pregnancy period. 21.36% think that infantile diseases of the children are the causes of the retardation. According to 14.56% parents, the retardation is due to difficult and defective birth process. 23.30% mentioned other reasons. It was not possible to know the opinion of 21.36% parents.

In the urban areas, 22.92% parents think that the causes of retardation are illness of mothers during pregnancy period. 47.92% think that infantile diseases of the children are the causes of the retardation. According to 23.61% parents, the retardation is due to difficult and defective birth process. 3.47% mentioned other reasons. It was not possible to know the opinion of 2.08% parents.

Both in urban and rural areas, many parents who mentioned 'other reasons' said that 'Bad Winds', 'Devil Powers', etc. during pregnancy periods of the mothers may be the causes. But the respondents were found not sure about these aspects.

**Figure-3.1. 3:** Types of treatment done

(Multiple answer)



$$\chi^2 = 72.04, df = 5, P < 0.01$$

When asked whether any treatment was given to the mentally retarded children, in both the urban and rural areas parents/guardians answered that they tried Allopathic, Faith Healing, Homeopathy and Ayurvedic treatments for their children. In urban areas all parents tried some treatments. But in rural areas 28.16% parents did not try any treatment and none of the parents went to the Psychiatrists.

In urban areas 100% parents tried Allopathic treatment. On the other hand in rural areas large majorities of the parents tried Homeopathic (68.93%), Faith Healing (53.40%), and Ayurvedic (63.11%) were tried by the parents, too.

It is seen that chi-square value of the above findings is 72.04 and statistically it is highly significant, which projects a clear picture how the parents attempt treatments or their mentally retarded children.

**Table-3.1.11: Severe diseases of the subjects until babyhood**

Diseases	(Multiple answer)			
	Urban N=144		Rural N=103	
	N	%	N	%
High Fever	88	61.11	73	70.87
Severe diarrhea	56	38.89	69	66.99
Respiratory problems and cough	43	29.86	57	55.34
Convulsion with high fever	56	38.89	43	41.75
Pneumonia	14	9.72	27	26.21
Meningitis and convulsion	21	14.58	05	04.85
Viral and bacterial infection	73	50.69	46	44.66
Polio	3	2.08	05	04.85
Information not available	11	7.64	28	27.18

$$\chi^2 = 5.22, df=8, NS$$

The parents/guardians were asked to mention the severe diseases suffered by the mentally retarded persons until their babyhood. They informed the researcher the names of the diseases or the symptoms, which are shown in the above table.

High fever and convulsion, diarrhea, respiratory problems, cough, pneumonia, meningitis, convulsion, infection, and polio were found as major diseases of the subjects. Information was not available from 27.18% in the rural and 7.64% in the urban cases. Though the chi-square test in contingency table is not significant the above table shows that most of the retarded persons were attacked by High fever, Diarrhea and Respiratory problems including cough until their babyhood. The researcher asked about the range of high temperature. But most of the rural guardians failed to provide information. It was understood through discussion that the families do not possess thermometers to measure the temperature. From the given description it is assumed that many children had very high fever followed by convulsion.

In the urban areas the families who have thermometers said sometimes the temperature raised up to 104<sup>0</sup>F. But in all cases it was not associated with convulsion. It was found that most of the children suffered for a prolonged period.



**Table- 3.1.12:** Professional levels of the treatment providers

Professional levels	(Multiple answer)			
	Urban N=144		Rural N=103	
	N	%	N	%
MBBS	109	75.69	12	11.65
Village Physician	0	0.00	76	73.79
Paramedic	0	0.00	37	35.92
Homeopathy	93	64.58	66	64.08
Ayurvedic	11	7.64	70	67.96
Information not available	0	0.00	28	27.18

$$\chi^2=195.8, df=5, P<0.01$$

While severely ill, the subjects were treated by different categories of physicians. The above table shows that in the rural areas only 11.65% were treated by MBBS, 73.79% were treated by village physician, 35.92% were treated by paramedic, 64.08% were treated by homeopathy and 67.96% were treated by Ayurvedic. Information was not available for 27.18% cases. The table presents that graduate physicians treated only 11.65% mentally retarded persons at the time of their severe illness, whereas in urban areas 75.69% were treated by graduate physicians and 64.58% by the homeopathic physicians. In urban areas none was treated by the paramedics or quack physicians.

In rural areas the researcher could not obtain treatment providers information of 27.18% subjects whereas in urban areas none was found without information.

The  $\chi^2$  value is significant at 0.01 level, which indicates that the finding is highly significant. It is assumed that in urban areas to most of the cases the treatment providers are graduate physicians or MBBS doctors. Whereas in rural areas most of the cases were treated by the village physicians.

**Table- 3.1.13:** Ability of the guardians to buy necessary medicine

Ability Range	Urban		Rural	
	N	%	N	%
Fully Capable	38	26.39	04	03.89
Capable	66	45.83	21	20.38
Moderately Capable	31	21.53	51	49.51
With difficulty	3	2.08	23	22.33
Unable	6	4.17	04	03.89
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=43.09, df=4, P<0.01$$

The parents/guardians were asked whether they are capable to buy all the medicine or complete treatment course of the subjects. The above table shows the ability levels of the parents/guardians of the subjects to purchase necessary medicines or complete treatment.

In the rural areas the number of the fully capable parents/guardians is only 3.89%; capable 20.38%; moderately capable 49.51%; with difficulty 22.33% and 3.89% are unable.

In the urban areas the findings are different. In urban areas 26.39% are fully capable, 45.83% are capable, and 21.53% are moderately capable. Among the urban cases only 2.08% can buy medicine with difficulty and 4.17% can't buy medicines.

**Table- 3.1.14(a):** Drug dependence of the subjects

Takes Medicine Regularly	Urban		Rural	
	N	%	N	%
Yes	98	68.06	03	2.92
No	46	31.94	98	95.14
Information not available	00	00.00	02	1.94
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 106.3, df=2, P>0.01$$

The researcher wanted to know from the parents/guardians whether their retarded child takes some medicine regularly or not. In the rural areas it was found that 2.92% said “Yes” and 95.14% said “No”. In urban areas 68.06% said “Yes” and 31.94% said “No”. From this finding it is understood that most of the mentally retarded persons of rural areas are free from drugs. The findings are different in urban areas. In the above table it is also seen that the  $\chi^2$  value is highly significant at 0.01 level.

**Table-3.1.14(b):** Nature of drug dependence

Types of drugs	Urban		Rural	
	N	%	N	%
Anti convulsants	57	58.16	3	100.00
Anti psychotics	18	18.37	0	0.00
Anti depressants	4	4.08	0	0.00
Anti anxiety	0	0.00	0	0.00
General and psychotropic drugs in combined type	5	5.10	0	0.00
Non-psychotropic drugs	14	14.29	0	0.00
<b>Total</b>	<b>98</b>	<b>100.00</b>	<b>3</b>	<b>100.00</b>

$$\chi^2 = 1.531, df=5 \quad NS$$

It was found that only 3 rural subjects are dependent on anti-convulsant drugs out of 103 rural subjects, whereas 98 out of 144 urban subjects are dependent on different types of drugs. The 14 subjects who are dependent on non-psychotropic drugs are consuming medicines for chronic cold, other allergy, dysentery, etc. During discussion it was found that easy availability of drugs and doctors in the urban areas jeopardized the situation.

**Table-3.1.15:** Prevalence of physical handicap conditions

Physical Problems	Urban		Rural	
	N	%	N	%
Yes	88	61.11	35	33.98
No	56	38.89	68	66.02
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2= 17.68 \text{ df}=1, P<0.01$$

The researcher has seen many mentally retarded persons both in urban and rural areas who have some physical problems in addition to mental retardation.

The above table shows that 33.98% mentally retarded persons of the rural areas have physical problems and 66.02% do not have physical handicap condition.

On the other hand in the urban areas 61.11% have physical handicapped conditions in addition to mental retardation. The findings project that the situation is slightly better in the rural areas.

**Table- 3.1.16:** Types of physical handicapped condition

Types	Urban		Rural	
	N	%	N	%
Physically handicapped and possess severe motor disorders	58	65.91	9	25.71
Partially physically handicapped	09	10.23	21	60.00
Speech and hearing impairment	21	23.86	5	14.29
<b>Total</b>	<b>88</b>	<b>100.00</b>	<b>35</b>	<b>100.00</b>

$$\chi^2=33.95, \text{ df}=2 \text{ P}<0.01$$

In the table above the types of physical handicapped condition of the subjects are shown. It is seen that 88 urban and 35 rural subjects have some physical handicapped condition in addition to mental retardation. It is also seen that motor disabilities of urban subjects are significantly more compared to the rural subjects. Speech and hearing impairment is also more among urban subjects.

### Education:

Many mentally retarded children go to the normal schools in their childhood in Bangladesh, then dropouts. To assess the problems and prospects of education of the subjects some questions were asked to the parents/guardians. Answers given by them are shown in the following tables.

**Table- 3.2.1:** Enrollment in primary schools

Response	Urban		Rural	
	N	%	N	%
Yes, the child was enrolled in the primary school/special school	73	50.69	35	33.98
No, never enrolled	54	37.50	60	58.25
Age of the subject is below 6 years or now over aged for schooling	17	11.81	08	7.77
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=10.41, \text{ df}=2, \text{ p}<0.01$$

All the parents/guardians were asked whether their children were enrolled in the primary schools or not.

In rural areas, it was found that 33.98% of them were enrolled in the primary schools and 58.25% were never enrolled in the schools. It was also found that 7.77% of the subjects are aged below 6 years.

In urban areas it is seen that 50.69% children were enrolled in primary schools. The percentage is more compared to the rural subjects.

**Table- 3.2.2:** Present status of school attendance

Going to school	Urban		Rural	
	N	%	N	%
Yes	66	90.41	09	25.71
No	07	9.59	26	74.29
<b>Total</b>	<b>73</b>	<b>100.00</b>	<b>35</b>	<b>100.00</b>

$$\chi^2=46.67, df=1, P<0.01$$

Those who were enrolled in schools or special schools were asked whether they are continuing education. There were 73 urban and 35 rural subjects who were enrolled in schools. In the table above it is seen that out of the 35 rural and 73 urban subjects 25.71% rural and 90.41% urban subjects are now attending schools. The researcher during observation also found that these subjects are relatively mild retarded compared to the others. They are also younger children. She also observed that in urban areas the scope of special schooling is significantly more compared to the rural areas. Secondly, due to social causes the urban parents are trying to send many mild retarded children to private schools with high tuition fees. Such social requirement is not there in the rural areas.

**Table- 3.2.3:** Reasons of school dropouts

Causes	Urban N=73		Rural N=35	
	N	%	N	%
Cannot perform the school works	39	53.42	32	91.43
Other children disturb them	13	17.81	20	57.14
Teachers asked them not to go	03	4.11	13	37.14
Other reasons	21	28.77	9	25.71

$$\chi^2=8.715, df=3, P<0.05$$

In the above table, findings related to school dropouts are shown. In rural areas, when the guardians were asked why the children do not go to the school, 91.43% of them said that the mentally retarded children could not perform the school works; 57.14% said that the children were disturbed by the others and 37.14% said that the teachers asked them not to come to the school. On the other hand, 25.71% informed that they understood that their children would not benefit from the school and the curriculum because of the handicapped conditions of the children. They also mentioned that the children were needed at home as helping hands to family works, etc.

The picture is different in urban areas. The rates of dropouts are lesser compared to rural areas. Those who dropouts have different pattern and percentage, too. In urban areas 53.42% dropped out, as they can not perform school works, 17.81% dropped out as other children disturb them. In urban areas only in 4.11% cases the teachers asked them not to go to the school.

**Table- 3.2.4:** Attempt to give education at home

Response	Urban		Rural	
	N	%	N	%
Yes	125	86.81	14	13.59
No	16	11.11	60	58.25
Information not available	3	20.08	29	28.16
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=132.1, df=2, P<0.01$$

The researcher wanted to know from the parents/guardians whether they took any initiative of giving education to the mentally retarded children at home. In the rural areas 13.59% of them said “Yes” and 58.25% said “No”. On the other hand, 28.16% parents did not give any specific answer.

In urban areas 86.81% parents took initiative to teach their mentally retarded children at home by private tutors. The percentage is significantly different from rural areas.

The researcher observed that easy availability of private tutors in urban areas is one of the major factors of this urban- rural difference. Secondly, in urban areas when private tutors are there the families get some mental satisfaction that something is being done for the children.



**Table-3.2.5:** Advice taken from counselor or special teacher

Response	Urban		Rural	
	N	%	N	%
Yes	66	45.84	11	10.68
No	75	52.08	60	58.25
Information not available	03	2.08	32	31.07
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=59.82, df=2, P<0.01$$

The researcher asked all the parents/guardians whether they consulted any counselor or special teacher for education of their mentally retarded children. The responses are presented in the above table. From the findings it is understood that in the rural areas only 10.68% parents/guardians consulted the matter with someone. Whereas in urban areas 45.84% consulted special teachers or counselors.

It is mentionable, most of the urban subjects of this study are affiliated with some Day Centre or Special School, whereas none of the rural subjects are affiliated with such centers.

**Table-3.2.6:** Transports to schools

Means of communication	Urban		Rural	
	N	%	N	%
Walking to schools	11	15.07	22	62.86
By school bus/van	39	56.16	0	00.00
Somebody accompany him/her	18	28.77	6	17.14
With others on Rickshaw van	5	6.85	4	11.43
In somebody's lap	0	0.00	2	5.71
In other way	0	0.00	1	2.86
<b>Total</b>	<b>73</b>	<b>100.00</b>	<b>35</b>	<b>100.00</b>

$$\chi^2=38.62, df=5, P<0.01$$

All guardians of 73 urban and 35 rural school or special school going children were asked how they send them to schools. Answers given by the guardians are shown in the table above. It is seen that 56.16% urban children go to schools by school bus or school van. None of the rural children enjoy such facilities.

In rural areas 62.86% children walk to the school by themselves as compared to 15.07% of their urban counterpart. In urban cases someone accompany 28.77% children as compared to 17.14% rural counterparts. In rural areas 11.43% go by public Rickshaw van as compare to 6.85% urban counterparts. In rural areas 5.71% children go to school in some one's lap and 2.86% go alone or use different other means to go to school.

In urban areas many children were seen affiliated with some Day Centre or special school. But they sometimes remain at home as most of their family members remain busy or pre-occupied to accompany them to Day Centres.

**Table-3.2.7(a):** Attitude towards special education

All the parents and guardians of the mentally retarded persons were asked whether special education is needed for their children. The respondents said either “Yes” or “No”. Following table shows the responses.

Response	Urban		Rural	
	N	%	N	%
Yes	141	97.92	71	68.93
No	03	2.08	32	31.07
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=41.48, df=1, P<0.01$$

The  $\chi^2$  test of contingency table is highly significant and it is seen that most of the parents of both urban and rural areas have positive attitude towards special education for the mentally retarded children.

**Table-3.2.7(b).** Positive attitude towards special education

All the 71 rural and 141 urban respondents, who possess positive attitude towards special education, were asked why special education is needed for the mentally retarded children. Different respondents mentioned different reasons. The answers were generalized into five categories of responses. Some respondents gave more than one reason for special education. Following table shows the responses.

Responses	Urban (N=141)		Rural (N=71)	
	N	%	N	%
That they can also obtain some education equivalent to primary education	102	72.34	12	16.90
That they can calculate, read and write	97	68.79	21	29.58
That they can cope with the simple problems of daily life	141	100.00	68	95.77
That they are not exploited by others	88	62.41	45	63.38
That they can at least communicate their problems	141	100.00	71	100.00

$$\chi^2=24.87, df=4, P<0.01$$

It is seen that there are some differences in the opinions given by the urban and rural parents/guardians. The opinions are shown in the above table. The  $\chi^2$  is highly significant at 0.01% level. From the above findings it is understood that all guardians feel that special education is needed to enable the mentally retarded children at least to communicate their personal problems to others. Secondly, the special education is needed that the retarded persons can cope with the problems of daily life.

**Table-3.2.8:** Types of education and curriculum

All the parents/guardians were asked to mention what type of education is needed for the mentally retarded children and what should be the curriculum of such education. Only 35 rural and 73 urban guardians provided some answers. The given answers were categorized into four different answers as shown in the following table.

Views	(Multiple answers)			
	Urban (N=73)		Rural (N=35)	
	N	%	N	%
The education should be equivalent to general primary education	66	90.41	29	82.86
The curriculum should be special to teach them only the basic things which are needed for their survival	72	98.63	33	94.29
Curriculum and syllabus must have to be different for individual child. These should be child centered special education	27	36.99	11	31.43
Some portion of the education will be general. Some portion be designed for individual children	38	52.05	18	51.43

$$\chi^2=0.091, df=3 \text{ NS}$$

The  $\chi^2$  value of the findings of the above table is not significant, so it can be said that the parents are confused related to the type of education needed for the mentally retarded children. They are confused with the contents of curriculum of such education.

**Table-3.2.9:** Promoters of special education

Promoters	(Multiple answers)			
	Urban N=141		Rural N=71	
	N	%	N	%
Central Government	97	68.79	43	54.70
Union Parishad or local Government	00	00.00	36	48.71
NGOs	83	58.86	27	39.31
The families of all the retarded persons	17	12.06	18	25.35
Somebody else but now	12	8.51	11	15.49
I do not know				
Do not know	26	18.44	9	12.68

$$\chi^2=70.35, df=5, P<0.01$$

The researcher asked the parents/guardians of the 71 rural and 141 urban children who answered “Yes” to question No. 3.2.7(a) that who should promote the special education for the mentally retarded children. The statements given by the respondents are shown in the above table. It is seen that 54.70% rural and 68.79% urban respondents said Central Government; 48.71% rural and none of the urban respondents said Union Parishad or Local Government; 39.31% rural and 58.86% urban respondents said NGOs; 25.35% rural and 12.06% urban respondents said that the families of all the retarded persons should become promoters. 12.68% rural and 18.44% urban respondents said that they do not know who should sponsor such education. On the other hand 8.51% urban and 15.49% rural respondents said that such special education be promoted by someone else other than the Government, Local Government or NGOs, but they do not know who it should be. After lot of discussion, the researcher could understand that they expect some philanthropist should take initiative to set-up such special schools.

The chi-square test of independent in contingency table is highly significant and majority of the parents want that the promoters should be the Central Government.

**Table- 3.2.10: Centre of special education**

When all the 71 rural and 141 urban parents/guardians were asked where such special education centers should be located they gave different suggestions. Following table shows the responses.

Location of special education facilities	Urban		Rural	
	N	%	N	%
Integrated with the Government primary schools but in separate class rooms	43	30.50	41	57.75
Segregated special schools	64	45.39	19	26.75
In the houses of the mentally retarded children.	00	00.00	9	12.68
One centre for all the children of the entire mouza				
In other places (Residential homes run by the Government or NGO, Special teachers should come to individual child's home or for 3-5 children	34	24.11	2	2.82
<b>Total</b>	<b>141</b>	<b>100.00</b>	<b>71</b>	<b>100.00</b>

$$\chi^2=30.91, df=3, P<0.01$$

The  $\chi^2$  value of the above mentioned findings is highly significant at 0.01 level. It is understood that a good number of the urban parents (45.39%) prefer segregated special schools. On the other hand most of the rural parents (57.75%) prefer integrated special classes inside the Government primary schools but in separate class rooms.

**Table-3.3.1(b):** Abilities to do economic activities of the subjects

All the 78 rural and 69 urban respondents who said “Yes” to engage the subjects in economic activities were asked to mention the names of works the retarded persons can do. Different respondents mentioned different kinds of works. Some respondents mentioned more than one activity. These are shown in the following table.

Activities	(Multiple answers)			
	Urban (N=69)		Rural (N=78)	
	N	%	N	%
Farming or in agriculture works	34	49.27	32	41.03
Feeding the cattle	9	13.04	29	37.18
Can help in marketing or selling agricultural goods	3	4.35	08	10.26
Can do household activities (cleaning the home, washing cloths, washing utensils, assist in the kitchen, etc.)	7	10.14	22	28.21
Poultry rearing	21	30.43	15	19.23
Sewing	53	76.81	04	5.13
Can work in packing section of large industries	43	62.32	0	00.00
Can become worker in assembling section in industries	31	44.93	1	1.28
Can become security guards or peons or tea-boys in offices	42	60.87	6	7.69
Others: Can look after the smaller children, can help during harvesting, etc.	2	2.89	13	16.67

$$\chi^2=41.7, df=9, P<0.01$$



**Table-3.3.2(a): Self-sufficiency of the subjects**

Responses	Urban		Rural	
	N	%	N	%
Yes, some initiatives were taken	116	80.56	15	14.56
No, did nothing	28	19.44	88	85.44
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 105, df = 1, P < 0.01$$

All the parents/guardians were asked whether they took any initiative to make their children self-sufficient or independent. 14.56% rural and 80.56% urban parents replied “Yes, some initiatives were taken”. Whereas, 85.44% rural and 19.44% urban parents replied “No, did nothing”. It is seen from the data presented in the above table that large majority of the rural parents did not take any initiative to make the mentally retarded children self-sufficient or independent.

In urban areas many parents bought houses, lands, etc. for their mentally retarded children with the hope that when they become adults some income should come as rent of these lands, houses, etc.

**Table-3.3.2(b): Steps taken**

All the 15 rural and 116 urban respondents, who said, “Yes” to question No.3.3.2 (a) were asked to mention the steps taken. They mentioned different steps. Some of them answered more than one step. Following table shows the answers.

Steps taken	(Multiple answers)			
	Urban (N=116)		Rural (N=15)	
	N	%	N	%
Bought some cows and were given to them for rearing at home	0	00.00	06	40.00
Some fruit trees were planted and they maintain the trees	0	00.00	04	26.67
Poultry at home	6	5.17	01	6.67
Being trained in agriculture works	0	00.00	05	33.33
Handicrafts manufacturing	29	25	03	20.00
Assist in family business. Mainly learning to measure goods at family shop situated in the market or very close to home	31	26.72	02	13.33
Female child learning how to boil and dry paddy	0	00.00	03	20.00
Being skilled in bamboo house building, clay house building, etc.	0	00.00	02	13.33
Now getting training in sheltered workshops	37	31.90	00	00.00
Parents / guardians showing them how to collect rents of houses/shops, etc. which they own	19	16.38	2	13.33
Visiting packaging units of industries and helping as apprentice	09	7.76	00	00.00
Going to offices, establishments where they can work as guards, tea-boys, etc. in future	13	11.21	00	00.00

$$\chi^2=51.45, df=11, P<0.01$$

**Table-3.3.3(a):** Scope of employment in the locality

Responses	Urban		Rural	
	N	%	N	%
Yes, there are some opportunities	66	45.83	69	66.99
No, there is nothing	78	54.17	34	33.01
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=10.85, df=1, P<0.01$$

All the parents were asked whether the retarded persons have any employment opportunity in their own locality. It is seen from the above table that 66.99% rural and 45.83% urban respondents said, "Yes". On the other hand 33.01% rural and 54.17% urban respondents said "No".

**Table-3.3.3(b):** Different employment opportunities of the subjects

All the 69 rural and 66 urban guardians who said that there are employment opportunities in their locality were asked to mention the opportunities. The given answers are shown in the following table.

Opportunities	Urban		Rural	
	N	%	N	%
Can involve in agricultural works	3	4.55	32	46.38
Establish cottage industries	18	27.27	4	5.80
Can manage small shops attached to their homes	2	3.03	15	21.74
Can involve them as a helping hand in the shops/offices	43	65.15	18	26.08
<b>Total</b>	<b>66</b>	<b>100.00</b>	<b>69</b>	<b>100.00</b>

$$\chi^2=41.69, df=3, P<0.01$$

**Table-3.3.4(a): Present employment status**

Employment status	Urban		Rural	
	N	%	N	%
Yes, he/she is already employed	13	9.03	19	18.45
No, not employed	131	90.97	84	81.55
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=4.724, df=1 P<0.05$$

All the guardians were asked whether the mentally retarded persons are employed or not, at present. The given answers are shown in the above table. It is seen that 9.03 % urban and 18.45 % rural respondents said, "Yes". On the other hand 81.55 % rural and 90.97 % urban respondents said "No". It is seen from the table, the percentage of the employed mentally retarded persons are very low at present.

**Table-3.3.4(b): Percentage of job types**

Though the researcher observed that many retarded persons of the present study are able to do some works, only 19 rural and 13 urban subjects were found engaged in jobs. Following table shows the nature of jobs done by these subjects.

Working places	Urban		Rural	
	N	%	N	%
In agricultural works of own family	0	0.00	10	52.63
In small shop attached to the house	0	0.00	03	15.79
As a cowboy in others family	0	0.00	02	10.53
As a part-time labor in fish-firm	0	0.00	04	21.05
Supporting hands in parental office/ shop/ business	10	76.92	0	00.00
As full-time worker in packing section of industries	3	23.08	0	00.00
<b>Total</b>	<b>13</b>	<b>100.00</b>	<b>19</b>	<b>100.00</b>

$$\chi^2=10.26, df=5 \text{ NS}$$

**Table-3.3.5:** Principal causes of unemployment as viewed by the guardians

Causes	Urban		Rural	
	N	%	N	%
Unable to do any work	20	15.27	15	17.85
Lack of job opportunity	24	18.32	19	22.62
Under aged	31	23.66	33	39.29
Other reasons: can not concentrate, hyperactive, depressed, physically handicapped, etc.	22	16.79	11	13.10
Communication and transport problem	34	25.95	06	7.14
<b>Total</b>	<b>131</b>	<b>100.00</b>	<b>84</b>	<b>100.00</b>

$$\chi^2=4.88, df=4, NS$$

The researcher has seen that many adult mentally retarded persons are not employed. When asked why the mentally retarded persons are not employed, the respondent/guardians mentioned many causes behind their unemployment. These causes are shown in the table above and are self-explanatory.

**Table-3.3.6:** Steps needed to create employment opportunities

Steps needed	(Multiple answers)			
	Urban (N=144)		Rural (N=103)	
	N	%	N	%
Vocational training	76	52.77	67	65.05
Special education	80	55.55	47	45.63
Special financing	63	43.75	52	50.49
Can't answer	12	8.33	39	37.86

$$\chi^2=5.26, df=3 NS$$

The researcher wanted to know what steps are necessary to create employment opportunities for the mentally retarded persons. The parents/guardians mentioned some measures that are shown in the table above. It is seen that 65.05% rural and 52.77% urban parents mentioned vocational training; 45.63% rural and 55.55% urban parents mentioned special education; 50.49% rural and 43.75% urban parents mentioned special financing. 37.86% rural and 8.33% urban parents could not answer the question.

**Table-3.3.7:** Expected organizations to create employment opportunity  
(Multiple answers)

Organization	Urban N=144		Rural N=103	
	N	%	N	%
Government	133	92.36	82	79.61
Union Parishad /Municipal committee	0	00.00	61	59.22
NGOs	72	50.00	72	69.90
Others: family, friends, philanthropists, etc.	64	44.44	17	16.50
Can't answer	07	4.86	23	22.33

$$\chi^2=74.66, df=4, P<0.01$$

All the respondents were asked to mention the names of organizations they expect can create job opportunities. The answers are shown in the table above. It is seen that 79.61% rural and 92.36% urban parents expect the Government; 59.22% rural and none of the urban parents expect the Union Parishad or local government; 69.90% rural and 50.55% urban parents expect the NGOs will create such opportunities. 22.33% rural and 4.86% urban respondents could not answer the question.

The 16.50% rural and 44.44% urban respondents who said "Others", during interview, mentioned that family, friends, philanthropists, etc. can create job opportunities for the mentally retarded persons in their own localities.

**Table-3.3.8:** Suitable vocational training

Vocational training	Urban N=144		(Multiple answers) Rural N=103	
	N	%	N	%
Farming and agriculture	32	22.22	83	80.58
Carpentry and wood works	67	46.53	28	27.18
Household works	9	6.25	38	36.89
Poultry	41	28.47	42	40.78
Cattle firming and dairy	2	1.39	34	33.01
Family business	43	29.86	11	10.68
In handicrafts	68	47.22	17	16.50
Small shop attached with the house	56	38.89	22	21.36
Can't answer	27	18.75	17	16.50

$$\chi^2=65.58, df=8, P<0.01$$

The researcher wanted to know from the parents/guardians which vocational training is suitable for the mentally retarded persons. Their views are shown in the above table. It is seen that farming; carpentry; household works; poultry; dairy; family business; handicrafts; and small shops were suggested by the parents/guardians. Some parents /guardians could not answer the question.

**Table-3.3.9(a):** Necessity of work involvement

Views	Urban		Rural	
	N	%	N	%
Yes	111	77.08	78	75.73
No	33	22.92	25	24.27
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=0.061, df=1, NS$$

The researcher asked all the guardians to mention their views whether it is necessary for the mentally retarded persons to involve in works according to their abilities. All parents /guardians could not provide answers. However, large majority of the parents /guardians said, "Yes", it is necessary for the mentally retarded persons to remain involved in some works.

**Table No. 3.3.9(b):** Reasons of work involvement

All the respondents who said that the retarded persons should participate in works or jobs mentioned different reasons to support their own views. The answers were generalized into three categories of responses. Following table shows the response.

Reasons	Urban		Rural	
	N	%	N	%
Financial support is necessary to survive. The retarded persons will be able to earn money through works. They will be independent.	31	27.93	42	57.78
If they are in work, they will have better mental condition and physical condition. They will not be exploited.	63	56.75	15	18.89
They will not become burden of family, society and country. If they are in work, they will be able to contribute to the national economy.	17	15.32	21	23.33
<b>Total</b>	<b>111</b>	<b>100.00</b>	<b>78</b>	<b>100.00</b>

$$\chi^2=26.67, df=2, P<0.01$$



## Housing:

The researcher asked 10 major questions and some corresponding questions to the parents/guardians related to housing of the mentally retarded persons. Answers given by the parents/guardians regarding the housing are presented in the following tables.

**Table-3.4.1(a):** Persons with whom the subjects live

Living with	Urban		Rural	
	N	%	N	%
Parents	101	70.14	84	81.55
Others	43	29.86	19	18.45
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=4.161, df=1, P<0.05$$

The above table shows the persons with whom the Mentally Retarded persons live at present.

In the rural areas 81.55% live with their parents and 18.45% live with others (brothers, siblings, husbands, wives, etc.). It was found that in urban areas 70.14% subjects live with their parents and 29.86% live with others. The “others” include siblings, uncle, aunt, grand parents, etc. but not any residential home.

It is also seen that both in urban and rural areas most of the Mentally Retarded persons live in their parental homes. The researcher also observed that many aged mentally retarded persons live in their parental homes, with aged siblings, uncles, aunts, etc. in the absence of their parents. She also observed that the living and interpersonal relations are more congenial in rural areas, compared to urban areas.

**Table-3.4.1(b): Living places**

Living places	Urban		Rural	
	N	%	N	%
Integrated with other members of the family	124	86.11	96	93.20
Separately	20	13.89	07	06.80
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=3.103, df=1, NS$$

The guardians were also asked whether the mentally retarded persons should live together with other family members or separately. The given answers are presented in the above table. It is seen in the above table that 93.20% rural and 86.11% urban mentally retarded persons live together with others in their own families. Only 6.80% rural and 13.89 % urban mentally retarded persons live separately. Those who live separately actually live in separate rooms mostly attached to the main houses.

**Table-3.4.2(a): Bed room status of the subjects**

Bed room status	Urban		Rural	
	N	%	N	%
Yes, there is an independent room for him/her	63	43.75	31	30.10
No, she/he lives in some room with others	81	56.25	72	69.90
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2=4.748, df=1, P<0.05$$

The researcher asked the parents/guardians whether the retarded child has a separate bedroom to live in. In rural areas 30.10% respondents said “Yes” and 69.90% said “No”. In urban areas 43.75% said “Yes” and 56.25% said “No”. From the findings it is understood that most of the retarded persons live in common bedrooms with other family members. However, more urban subjects have separate bed rooms compared to the rural subjects.

**Table-3.4.2(b):** Location of the separate bedrooms

It was found that 30.10% rural and 43.75% urban retarded persons live in separate or independent bedrooms. The researcher wanted to know the location of such rooms. The answers given by the guardians are shown in the following table.

Location	Urban		Rural	
	N	%	N	%
Integrated inside the same house	54	85.71	21	67.74
In a segregated room specially made for him/her	9	14.29	10	32.26
<b>Total</b>	<b>63</b>	<b>100.00</b>	<b>31</b>	<b>100.00</b>

$$\chi^2 = 4.161, df=1, P < 0.05$$

In the table above it is seen that 85.71% urban and 67.74% rural subjects who have separate bed rooms possess such bed rooms which are integrated inside the main bed room areas of the houses. On the other hand 14.29% urban and 32.26% rural subjects have such separate bed rooms which are not integrated with the main bed room areas of their houses.

Out of 9 urban cases 7 are of very high socioeconomic status. Remaining 2 are of middle class families, but because of severe handicapped condition of the cases, the guardians segregated their bedrooms from other's bedrooms. Among rich families such bedrooms are usually in the top floors of the residence.

In rural areas, the separated bed rooms are segregated from the main houses. In urban areas 3 persons were found who are not adult but live in segregated bed rooms, under the care of nursing staff. In rural areas all the 10 cases are adult male subjects and can take care of themselves in separate bed rooms.

**Table-3.4.3(a):** Types of the houses

Types of house	Urban		Rural	
	N	%	N	%
Apartments / Pucca House	125	86.81	00	00
Mud-built straw-roofed House	0	00	43	41.75
Mud-built Tinished House	0	00	51	49.51
Semi-Pucca House	19	13.19	8	7.77
Hut, bamboo made house	0	00	01	0.97
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 220.8, df = 4, P < 0.01$$

Categories of the houses where the mentally retarded persons are now living are shown in the above table. It is seen in the table that none of the rural subjects live in apartments/pucca houses. Whereas, 86.81% urban cases have pucca houses. On the other hand, 41.75% rural and none of the urban cases live in mud-built straw-roofed houses. 49.51% rural and none of urban cases live in mud-built tin shed houses. 7.77% rural and 13.19% urban subjects live in semi-pucca houses. 0.97% rural and none of the urban subjects live in hut.

The findings shown above related to the percentage of types of houses of the mentally retarded persons are not different from the non retarded persons. In Bangladesh, the percentage of general housing patterns is similar to the above findings.

**Table-3.4.3(b):** Quality of beds

Bed	Urban		Rural	
	N	%	N	%
Standard beds	108	75.00	78	75.73
Below standard beds	36	25.00	25	24.27
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 0.017, df = 1, NS$$

The parents/guardians were asked where their mentally retarded child sleeps. In rural areas 75.73% respondents said that they sleep "On the bed" and 24.27% said "below standard" beds or "on the floor".

The findings are more or less similar in urban and rural areas. But in urban areas who live in below standard beds are mainly because of severe physical handicapped condition of the subjects. Whereas in rural areas it is not always the severe handicapped condition of the subjects.

**Table-3.4.4:** Persons cleaning their rooms

Persons	Urban		Rural	
	N	%	N	%
Himself / herself or by siblings	52	36.11	48	46.60
Somebody else (mother, siblings, servant)	92	63.89	55	53.40
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 3.743, df = 1, P < 0.01$$

The respondents were asked who cleans the bedrooms of the subjects. The information given is presented in the above table. It is seen from the table that the rooms of 46.60% rural and 52.78% urban mentally retarded persons are cleaned by themselves or by their siblings. On the other hand somebody else cleans the rooms of 47.22% urban and 53.40% rural mentally retarded persons.

**Table-3.4.5:** Disturbed sleeping places

Status	Urban		Rural	
	N	%	N	%
Yes, Sleeping here and there	09	6.25	11	10.68
No	135	93.75	92	89.32
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 0.906, \text{ df} = 1, \text{ NS}$$

When asked whether the mentally retarded persons sleep here and there because of the inconvenience of living places at home, 10.68% rural and 6.25% urban respondents said “Yes”. On the other hand 89.32% rural and 93.75% urban respondents said “No”.

It was observed that there are some retarded persons who sleep here and there in rural areas for some difficulties at home. When asked, the respondents informed that they sleep at school varandah, market place, and at other’s home, etc. But in the urban cases they sleep in their own home but sometimes the rooms are changed due to arrival of guests, etc.

**Table-3.4.6(a): Standard of Dress**

The researcher when visited the houses of the subjects asked them to show her their best dresses. The mentally retarded persons were very enthusiastic to show her their dresses. She assessed the dresses by herself and rated them in the following table.

Standards of the dresses	Urban		Rural	
	N	%	N	%
Higher standard	74	51.39	9	8.74
Normal for the community	49	34.03	53	51.46
Below standard	19	13.19	28	27.18
Poor	02	1.39	13	12.62
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 43.1, \text{ df} = 3, \text{ P} < 0.01$$

The researcher found that most of the rural retarded children aged 9-10 years have at least 2-3 sets of dresses. Male children aged 11-12 years have 2-3 lungees and 2-3 shirts. Female children have 2-3 frock, and sallower or petticoats. Some of them have 1-2 sets of quality dresses. The retarded children wear these quality dresses during special occasions or while going to their relative's houses. During the study, the researcher observed that many retarded children wear dirty dresses most of the time. Again, some of them have no sandal or shoes.

Whereas in the urban areas she found that most of the mentally retarded children of all social classes possess dresses of same standard like their other siblings. Only among urban very poor families some mentally retarded children do not have quality dresses.

**Table–3.4.6(b): Standard of Food**

The parents/guardians were asked whether the food given to their retarded children are of equal standard like other members of the family. The answers are shown in the following table, which are self-explanatory.

Answers	Urban		Rural	
	N	%	N	%
Yes, they are given the same standard food.	135	93.75	96	93.20
Sometimes, they are little ignored in food	09	6.25	07	6.80
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 0.03, \text{ df}=1 \text{ NS}$$

But the researcher found that some urban children are sent to special schools with foods from homes which are of inferior quality compared to their siblings who are going to normal schools. During home visits the researcher also found that some of the mentally retarded children are not given the best part of the food which is given to their siblings. However, these are individual cases.



**Table-3.4.7.** Proper living place for the mentally retarded person according to parents

Places	Urban		Rural	
	N	%	N	%
Own family	89	61.81	90	87.38
Group home	53	36.80	03	2.91
Somewhere else	2	1.39	10	9.71
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 44.4, df = 2, P < 0.01$$

The researcher asked all the parents/guardians that which is the proper living place for the mentally retarded persons. Their views are presented in the above table. 61.81% urban and 87.38% rural parents/guardians think that the mentally retarded persons should live with their own family. 36.80% urban and 2.91% rural parents/guardians think that they should live in the group homes. 1.39% urban and 9.71% rural parents/guardians think that they should live somewhere else. It is seen that though most of the parents/guardians feel that the mentally retarded persons should live with their own families, yet there are some parents/guardians who think that they should live somewhere else. When asked which places they mean by “somewhere else”, the respondents could not give any suitable answer. Actually they did not think the issue that seriously. During repeated questions some of the poor rural guardians said that they should be given independent status of living and loitering.

The two urban parents said that they can provide some money and hired people should take care of the mentally retarded persons either at the houses of the hired people’s houses or at some rented houses.

The group home concept was found understood by most of the educated urban parents but not by the rural parents. During detail discussion the researcher perceived that these urban parents have some ideas of group home of western countries and India. They want such establishments primarily should be initiated by a group of parents. Then they should try for grants or subsidies from the government.

**Table-3.4.8(a):** Interest of the family members towards integrated living

Opinion	Urban		Rural	
	N	%	N	%
Yes, strongly recommend integrated living	106	73.61	71	68.93
No, some special arrangement is needed	38	26.39	32	31.07
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 0.647, \text{ df} = 1 \quad \text{NS}$$

When asked if the other members of the family agree to live with the mentally retarded persons in the same house. 68.93% rural and 73.61% urban respondents said, “Yes”. 31.07% rural and 26.39% urban parents said “No”. It is understood that in some families, some members do not like to live with the mentally retarded persons in the same house both in urban and rural areas.

It was observed that the siblings until their own marriage recommend integrated living. But when the siblings get married and have their own children prefer that the subjects or they themselves should live separately. Actually the married siblings themselves want to live separately leaving the parents and the mentally retarded siblings at the old parental houses. However, the nature, number and seriousness of such opinions are of individual families and can not be generalized.

**Table-3.4.8(b):** Negative attitudes of the family members towards integrated living

Those who said 'No' to the above question, the researcher asked all of them why some of the members of the family do not want to live with the retarded persons. The respondents mentioned many reasons. All the answers of the respondents were generalized into three answers. These are shown in the following table.

Responses	Urban		Rural	
	N	%	N	%
They feel that the severely retarded persons are burdens	25	65.79	7	21.88
In joint families, they think that if their own children live with the retarded subjects their own children may behave like the retarded persons.	3	7.89	16	50.00
The retarded persons are having social adjustment problems. They create many peculiar problems in the family.	10	26.32	9	28.12
<b>Total</b>	<b>38</b>	<b>100.00</b>	<b>32</b>	<b>100.00</b>

$$\chi^2 = 18.7, \text{ df} = 2, P < 0.01$$

**Table-3.4.9:** Place where the mentally retarded person will live in the absence of parents

Place	Urban		Rural	
	N	%	N	%
In the same place where he or she is living now, mostly the parental houses.	80	55.56	56	54.37
Elder brothers/sisters or other relatives	31	21.53	22	21.36
There are separate arrangements or separate houses	21	14.58	05	04.85
Uncertain	43	29.86	20	19.42
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 5.416, df = 3, NS$$

The researcher wanted to know from the parents/guardians of the mentally retarded persons where they will live in the absence of the parents/guardians. The responses of the parents are shown in the above table.

54.37% rural and 55.56% urban parents said that they should live in the same place where he or she is living now. 21% parents of the urban and rural areas said that they should live with their elder brothers/sisters or other relatives like uncle, aunt, etc. 4.85% rural and 14.58% urban parents said that there are separate arrangements or separate houses. 19.42% rural and 29.86% urban parents are uncertain towards this future living place issue.

### Social Security:

At present Bangladesh Government is not providing any pension or social welfare benefit to the Mentally Retarded persons. Sometimes they are subjects of stigma in family and society, too. The researcher tried to investigate the situation in the study areas. Following tables show the findings.

**Table-3.5.1:** Attempt to hide the problems of the mentally retarded

Attempt	Urban		Rural	
	N	%	N	%
Yes, conceal the problems of the mentally retarded children to others	63	43.75	02	01.94
No, disclose the problems of the mentally retarded children to others	81	56.25	101	98.06
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 54.13, df = 1, P < 0.01$$

The parents/guardians were asked if they conceal their problems related to the retarded children to others. 1.94% rural and 43.75% urban respondents said that they conceal the problems of their mentally retarded children to others. On the other hand 98.06% rural and 56.25% urban parents said that they disclose the problems of their mentally retarded children to others.

The two rural respondents were asked why they try to conceal the problems of their mentally retarded children to others. They informed the researcher that their social prestige might be jeopardized if they disclose the retardation of their children to others. They think that in future, negative impact may happen on the other children of the family. But the researcher observed that in the rural areas it is really difficult to conceal the existence of a handicapped child to the neighbours.

In the urban areas, the researcher observed that the families, especially the middle class families try to confine their mentally retarded children inside their home. The poor mentally retarded children loiter in their neighbourhood in urban areas.

**Table-3.5.2:** Others' behaviour with the mentally retarded subjects

Behaviour	Urban		Rural	
	N	%	N	%
Behave normally	80	55.55	55	53.40
Annoy him/her	25	17.36	31	30.10
Avoid him/her	08	5.56	12	11.65
Irritate, humiliate, etc.	31	21.53	05	4.85
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 7.102, df = 3 \quad \text{NS}$$

How other people behave with the mentally retarded persons as perceived by the guardians is presented in the above table. It is seen that 53.40% rural and 55.55% urban respondents said that other people behave normally. 30.10% rural and 17.36% urban parents said that other people annoy them. 11.65% rural and 5.56% urban parents said that other people avoid them. 4.85% rural and 21.53% urban parents said that other people irritate or humiliate them. However, it is seen that 53.40% rural and 55.55% urban mentally retarded persons get normal behaviour from others.

**Table-3.5.3(a):** Participation in social events

Participation	Urban		Rural	
	N	%	N	%
Yes, they accompany their parents while visiting a relative's house or attend different ceremony	61	42.36	57	55.34
No, they are not with their parents while visiting a relative's house or attending ceremonies.	83	57.64	46	44.66
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 4.054, df = 1, P < 0.05$$

The parents/guardians were asked if they take their mentally retarded children with them when they visit any relatives' house or attend any ceremony. 55.34% rural and 42.36% urban respondents said that they take their mentally retarded children while they visit relative's houses or attend different ceremonies. On the other hand, 44.66% rural and 57.64% urban parents said that they do not take their handicapped children while visiting relative's houses or ceremonies.

**Table-3.5.3(b):** Causes of non-accompany in social events

All the 46 rural and 83 urban guardians who do not take their mentally retarded children with them were asked why they do not take them to relative's houses or to different ceremonies. Respondents mentioned different causes. Some respondents mentioned more than one cause. The given answers were generalized into four categories. These are shown in the following table.

Causes	(Multiple Answers)			
	Urban ( N=83)		Rural (N=46)	
	N	%	N	%
Mentally retarded persons cannot show appropriate behavior. Extra caretaker is needed to look after them.	40	48.19	29	63.04
Social status of the guardians sometimes jeopardize, others get annoyed. They sometimes create trouble in the environment of the ceremony.	32	34.94	12	26.09
They can't join because of their serious handicapped condition	37	44.58	9	19.57

$$\chi^2 = 6.952, df = 2, P < 0.05$$

**Table-3.5.5:** Care takers of the handicapped citizens

Responses	Urban		Rural	
	N	%	N	%
The members of the family	42	29.17	56	54.37
Government	98	68.06	22	21.36
NGOs	03	2.08	9	8.74
Some other else: relatives, neighbors, etc.	01	0.69	16	15.53
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 42.04, df = 3, P < 0.01$$

All the parents/guardians were asked who should take care of the handicapped persons. The parents/guardians mentioned different organizations which are shown in the above table. 54.37% rural and 29.17% urban parents/guardians said that the family members themselves should take all care. 21.36% rural and 68.06% urban guardians said that government should take all care. 8.74% rural and 2.08% urban guardians mentioned NGOs should take care of them. On the other hand 0.69% urban and 15.53% rural guardians mentioned "others". It is seen that most of the parents/guardians think that the responsibility of maintenance of the mentally retarded persons should not only be given to the family members, also the Government should take some of the responsibilities.



**Table-3.5.6(a):** Need of government subsidy

<b>Responses</b>	<b>Urban</b>		<b>Rural</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
Yes, Government subsidy is necessary.	74	51.38	93	90.29
No, Government subsidy is not necessary.	70	48.62	10	9.71
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 41.5, df = 1, P < 0.01$$

Parents/guardians were asked whether government grants, supports are necessary for the mentally retarded persons. Opinions of the parents/guardians are shown in the above table. It is seen that 51.38% urban and 90.29% rural guardians said that Government subsidy is necessary. During discussion with the respondents it was understood that some financial support to the families for the handicapped persons from the government will increase social status of these persons in their own families and in society.

**Table-3.5.6(b):** Government support is necessary

All the 93 rural and 74 urban respondents who said “Yes,” to question 3.5.6.(a) were asked why they thought government support is necessary for the mentally retarded persons. The respondents gave many answers. Some of them gave more than one answer. The answers are categorized into five answers as presented in the following table.

Responses	Urban (N=74)		(Multiple answers) Rural ( N=93)	
	N	%	N	%
Since they cannot participate in the financial activities like normal people, government grants are necessary for their maintenance.	63	85.14	52	55.91
It will help to buy medicine, clothes, essentials, etc. from such government grants. This will improve their living standard.	68	91.90	32	34.41
Government grants will help them to become self-sufficient.	37	50.00	19	20.43
Government grants like pension will increase their acceptability in family and society	74	100.00	80	86.02
Government grants will help parents to appoint nursing staff at home	46	62.16	0	00.00

$$\chi^2 = 4.509, \text{ df}=4 \text{ NS}$$

**Table-3.5.6(c): Government support is not necessary**

All the 10 rural and 70 urban respondents who said “No” to the question 3.5.6(a) were asked why they thought so. They gave many responses. Their answers were categorized into three groups and are presented in the following table.

Responses	(Multiple answers)			
	Urban (N=70)		Rural (N=10)	
	N	%	N	%
The family has a lot of money, so there is no need for government grants	41	58.57	6	60.00
If they are given government grants, they will grow as dependent on others.	10	14.29	02	20.00
Social prestige of the family may be jeopardized if the family receive government grants	53	75.71	07	70.00

$$\chi^2 = 0.229, df=2, NS$$

**Table-3.5.7(a): Feeling of social Problems**

Responses	Urban		Rural	
	N	%	N	%
Yes, they face many kinds of problems	102	70.83	73	70.87
No, they do not face any problem	42	29.17	30	29.13
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 5.05, df=1, P < 0.05$$

All the parents/guardians were asked whether they feel any social problem because of retardation of their children. 70.87% rural and 70.83% urban guardians said that they face many social problems. On the other hand, 29.13% rural and 29.17% urban guardians said that they do not feel so. In fact, most parents face some social problems of different degree and nature for the retardation of their child as shown in the following table.

**Table-3.5.7(b):** Categories of social problem

The parents face many problems in the society due to the retardation of their children. The parents were asked what type of problems they face. All the 73 rural and 102 urban respondents mentioned different problems, which are broadly categorized into five problems. The problems are shown in the following table.

Response	(Multiple answers)			
	Urban N=102		Rural N=73	
	N	%	N	%
Problem with their neighbors. Because of the retardation of their children sometimes the neighbors insult the parents for some innocent act of the subjects.	91	89.22	51	69.86
They cannot take part in different ceremonies for the severe handicapped conditions of their children.	26	25.49	36	49.32
The marriage of other normal children or other members of the family sometimes become a problem	09	8.82	19	26.03
Neighbour/close relatives/ friends do not understand what mental retardation is	80	78.43	07	9.59
Friends relatives speak about their handicapped children to others in their absence	73	71.57	06	8.22

$$\chi^2 = 45.16, \text{ df}=4, \text{ P}<0.01$$

**Table-3.5.8(a): Social opportunities**

Opportunities	Urban		Rural	
	N	%	N	%
Yes, they get all opportunities	42	29.17	57	55.34
No, they do not get all opportunities	102	70.83	46	44.66
<b>Total</b>	<b>144</b>	<b>100.00</b>	<b>103</b>	<b>100.00</b>

$$\chi^2 = 17.13, \text{ df} = 1, P < 0.01$$

When the researcher asked the parents/guardians of the mentally retarded children whether their children get the opportunities of social mixing, sports and pastime like others. In response 55.34% rural and 29.17% urban guardians said that they get all the opportunities. On the other hand 44.66% rural and 70.83% urban guardians said that they do not get all the opportunities. It is understood that many mentally retarded children are deprived from normal social interactions both in urban and rural areas in Bangladesh.

**Table-3.5.8(b):** Percentage of the mentally retarded children who are deprived of social events

The respondents who said “No” to the above question were asked why the mentally retarded children do not get the opportunities of social mixing, sports and recreation. The respondents described different things. The researcher generalized the answers into four categories. Which are shown in the table below.

Response	(Multiple answers)			
	Urban (N=102)		Rural (N=46)	
	N	%	N	%
Some normal children do not accept the retarded children to be their mates, because they cannot behave like the other normal children, or cope with them.	88	86.27	27	58.70
Others avoid the mentally retarded children. Many of them do not want to mix with them.	73	71.57	19	41.30
Sometimes, the mentally retarded children are annoyed and humiliated by others.	66	64.71	10	21.74
They do not have any special facilities in the community suitable to their levels.	76	74.51	07	15.22

$$\chi^2 = 4.808, \text{ df} = 3 \quad \text{NS}$$

**Table-3.5.9:** Problems of the female retarded persons as viewed by the parents

The parents of all the female subjects were asked what problems they face because of the mentally retarded condition of their children and what things they are concerned about. The parents of all the female mentally retarded persons mentioned some problems. These were generalized into four problems and are shown below.

Responses	Urban (N=144)		Rural (N=103)	
	N	%	N	%
They are worried that their children may be sexually abused. They are also worried that their children have no knowledge of protecting themselves.	89	61.81	77	74.76
The subjects are not conscious about their own cleanliness. Many of them are completely dependent upon others for their regular cleanliness.	42	29.17	41	39.81
Sometimes there are problems related to their marriage and those who get married face many problems in marital adjustment.	57	39.58	18	17.48
Child is too small and does not face problems now. But worried about future	10	6.94	06	5.83

$$\chi^2=13.18, \text{ df}=3, P<0.01$$

*Chapter-IV*  
*Discussion*



# Chapter IV

## Discussion

Until the decade of eighties of the last century, mentally retarded persons were concerned only by their own family members and close relations in Bangladesh. Community leaders and neighbors never felt that they have some responsibilities for them. The Government and its officers did not plan anything to uplift their conditions. Yet in most of the rural areas, which comprise the large part of the country, mentally retarded persons are not treated properly. In many places mentally retarded persons are subjects of social stigma, are humiliated and deprived of their basic rights. However, during last 25 years the attitude is changing slowly in the country, mostly in the urban areas, where the NGOs are promoting awareness among the people through seminars, symposiums, discussion, meetings, etc. But the overall rate of awareness development in the country is very slow.

The researcher observed that yet the concerned families feel that it is their sole responsibility to look after their mentally retarded members until their death. The parents, guardians and siblings expect that it could be better if the government or some other agencies could help them. But they are not sure what help can be requested and what can be achieved.

Until very recently the mentally retarded persons of Bangladesh had shorter life spans. Almost all the severe and profound mentally retarded persons died within their childhood. Those who survived longer are mild or moderately mentally retarded persons. They could develop in such a way that they were integrated in the community and were not considered as mentally retarded.

The population of Bangladesh is huge considering its habitable land areas. It is assumed that the country recently achieved self-sufficiency if food and clothes, but the government yet did not officially declare it free from these two basic needs. Though the foreign aid contribution is only 1.97% of the total GDP of the country, Bangladesh government is yet seeking aids from international funds for many of its development budget. Bangladesh is not a social welfare state. The state yet does not guarantee many basic rights of its citizen. Though the government introduced some

benefit programs for the aged people and the poor women in the country, large majorities of these two categories of people are yet not receiving any government benefit. During discussion with the government officials, the researcher understood that the concerned government officials are fully aware of the problems of the mentally retarded persons. But as there is no government support program for the handicapped people, they can not do anything for them.

It was found that large majorities of the mentally retarded persons pay different taxes to the government and all the adult mentally retarded persons are enlisted as voters in Bangladesh. According to the constitution of Bangladesh (section 15-d of part-II) they have rights to get complete care from the government. But they are deprived from their basic rights.

Bangladesh Government yet could not announce any policy program for the mentally retarded persons in the country. It is seen that relevant government departments do not know exactly how many people in this country are mentally retarded. Recently Bangladesh government has introduced some monthly benefit programs for the old aged and poor women in the country, and the researcher assumes that in near future the government will also introduce benefit programs for the handicapped citizens, too. It is very difficult to generalize the problems of the mentally retarded persons and each mentally retarded person has his/her unique problems and prospects. Therefore, it is not claimed that all the psychosocial problems of the mentally retarded persons were covered in this study. The researcher was face to face with all of them and their guardians at their own houses. She has observed each subject on several days in different situations. She made follow-up studies of different situations. Not only at their houses, she has observed them in agricultural fields, in roads, in the markets, during different types of interpersonal relations.

The following section of this chapter is a discussion on different aspects of the findings grouped under five broad sub-headings. These are Health, Education, Employment, Housing and Social Security. But before detail discussion the researcher attempts to discuss a little about the prevalence of mental retardation.

**Prevalence, awareness and detection:**

The majority of individuals with mental retardation have historically been classified as having mild, cultural/familial mental retardation. In developed countries, the prevalence of mild mental retardation appears to be lower than it is in the U.S. Percentages of mental retardation or mental handicap in Sweden, for instance, have been estimated to be between 0.3% and 0.7% (Grunewald, 1979; Golding, 1982; Halldin, 1984, Zigler and Hodapp, 1986). Interestingly, although the prevalence of mild mental retardation has been found to be lower in Sweden than in the U.S., the two countries have reported comparable percentages of severe mental retardation (Zigler and Hodapp, 1986). Sweden's low prevalence of mild mental retardation may seem surprising, given that at least some of the Swedish studies use a higher IQ cutoff (<80) to define this condition.

However, Sweden has few psychologists, and testing is not as widespread there as it is in the U.S. (Zigler *et al.* 1984). Additionally, Swedish prevalence estimates of mental retardation are based on the subjective opinions of teachers and clinicians, who are reluctant to label mild cognitively impaired children as mentally retarded (Zigler, 1987b). Since Sweden keeps a registry of individuals with mental retardation, many Swedish studies are population based, which may lead to more accurate population prevalence than that estimated in the U.S. In addition, Sweden is a Welfare State, and has many programs available for those with mild mental retardation. As a result, many of these individuals are cared for in the community, and may never even be thought of as having mental retardation until their IQs (at least males) are formally tested for entry into military service (Zigler *et al.* 1984; Zigler and Hodapp, 1986; Zigler, 1987b). When estimates from the community are combined with estimates from armed forces testing, the prevalence estimates for mental retardation increase to 2.21%, similar to that found in other countries (Zigler, 1987b). Other developed countries also have registries of mental retardation, which makes population based studies more feasible than in the U.S. The overall prevalence of moderate and severe mental retardation, arrested development or severe abnormality among children and adults in England has been found to range between 0.3% and 0.5 % (Wing, 1971, Holt and Huntley, 1973; Elliot *et al.* 1981; Goh and Holland, 1994). A study using a

surveillance registry in British Columbia found the overall mentally retarded prevalence rate to be similar (0.4%), with 0.1% mild, 0.1% moderate, 0.05% severe, 0.04% profound and 0.01% unspecified mental retardation (Herbst and Baird, 1983). In Ireland, using an IQ cutoff of 50 (severe mental retardation), the rate of mental retardation among adults 20-29 was found to range from 0.4 to 0.6% (Mallon *et al.* 1991).

In less developed countries, percentages of mentally retarded are generally found to be higher, from 1.6%-3.0% (Islam, *et al.* 1993). However, several recent studies have found the prevalence of mental retardation to be quite low. For example, in The People's Republic of China, the use of intelligence tests in several districts found a prevalence that ranged between 0.4% and 0.7% (Kuo-Tai, 1988).

Similarly, a study in Cape Town, South Africa, using administrative data, found the prevalence of severe mental retardation to be 0.3% (Finedlander and Power, 1982), and a population based study of prevalence in Bangladesh found a rate of 0.6% for severe mental retardation and 1.4% for mild mental retardation (Islam *et al.* 1993). Further, a study that went door-to-door in India, using the Binet-Simon scale to define mental retardation as an IQ<80, has indicated a prevalence rate of 0.4% in the general population and 1.0% among children (Satapathy *et al.* 1985).

It is not very clear how many people of Bangladesh are mentally retarded. The Government data is not well update. Secondly, there is no report of any National Survey. The reports published by the Bureau of Statistics are also ambiguous because the Bureau of statistics did not assess the real mental conditions of the persons included under mentally handicapped headings. It is assumed that Bureau of Statistic included all mentally ill, mentally retarded and persons with multiple handicapped conditions under the heading 'Mentally Handicapped' in the official reports. However, some independent sample surveys were done under private initiatives during 1988-2002 in different areas of Bangladesh and it was found that the prevalence rate did not exceed 0.5% of the population in any area.

**Health:**

People with mental retardation grow up and grow older and need good health and good health care, like any other person. But people with mental retardation may face extra problems in staying healthy and in finding the right health services when they are sick. In Bangladesh large majorities of the people are unaware of their rights, and duties related to education and health care. This problem is more complicated for the mentally retarded persons living in the rural areas.

Health problems are the most severe problems of the mentally retarded persons. It is seen that the parents of the handicapped babies observe the difficulties of their children but usually do not want to accept that their babies are handicapped. In most cases it is the medical doctors who finally declare that the child is handicapped. In table 3.1.6 of the preceding chapter, it can be seen that only 8.33% urban and 0.97% rural parents were able to know the problems during 0-2 years of their children. It was also observed that the large majority of the parents could not understand that their sons and daughters are retarded until they reached their childhood stage of life.

In Bangladesh, large majorities of the parents do not know the normal development pattern and developmental stages of the children. The researcher talked to the parents of the mentally retarded children during her study and found their ignorance and faulty understanding of the normal growth of the children. In reality when they see that the babies are not being able to walk, speak or communicate properly, only then they seek help of the medical and other professionals.

In table 3.1.7 (a) some important symptoms, which helped the parents to know that their child was mentally retarded, were shown. It was found that lack of social adjustment, inability to do school works and inability to perceive social situations are the most important symptoms that helped them to know that the children are mentally retarded. There are other symptoms, too. It was found that many children possess multiple handicapped conditions. When children possess multiple handicapped conditions, the parents perceive the reality earlier.

Previous studies suggested that a disturbed prenatal environment, resulting from mothers emotional problems, specially the anxiety, may cause a modification of the newborn infant's behaviour pattern. These disturbances are especially important during the later part of intrauterine life and may cause a state of hyperactivity and irritability in the new born infant (Peckos, 1957; Sontag, 1945). Prenatal environment has direct effect on the personality of the newborn. Glandular changes in the mother due to prolonged emotional strain affect the physical and mental development of the fetus. These "blood-borne" anxieties also carry over into the period of the new born and affect the infants adjustment to postnatal life (Sontag, 1945; William and Riley, 1950)

In this study it was seen (table 3.1.3) that 88.33% urban and 52.43% rural pregnant mothers had severe mental anxiety during pregnancy period.

In this study, through close interviews the researcher came to know that some mothers have taken tranquillizing drugs while they had severe anxiety. Since the molecules of these drugs can pass through the umbilical cord, it can directly affect the fetus. Use of strong chemicals and drugs may also be responsible for the birth of handicapped children.

Age of the mother at the time of conception is considered as a significant factor for the birth of a handicapped child. The scientists have already seen that if the mother is below 16 and above 35 years in age, the chances of giving birth of a child with chromosomal anomalies are very high. Therefore, in many western countries and in our neighbouring country India, the physicians always recommend prenatal diagnosis, specially Amniocentesis, when the mother is too young or old. Through Amniocentesis test the mother can know whether the fetus has any chromosomal anomalies or not. And she can ultimately come to a decision whether she will choose an abortion or not.

The incidence of Down syndrome rises with increasing maternal age. Many specialists recommend that women who become pregnant at age 35 or older undergo prenatal testing for Down syndrome. The likelihood that a woman under 30 who becomes pregnant will have a baby with Down syndrome is less than 1 in 1,000, but the chance of having a baby with Down syndrome increases to 1 in 400 for women

who become pregnant at age 35. The likelihood of Down syndrome continues to increase as a woman ages, so that by age 42, the chance is 1 in 60 that a pregnant woman will have a baby with Down syndrome, and by age 49, the chance is 1 in 12. But using maternal age alone will not detect over 75% of pregnancies that will result in Down syndrome (Hook and Lindsjo, 1978).

In this study, it is seen in table 2.12 in chapter II, that the large majority of the mothers were between 26 and 35 years in age when they conceived the mentally retarded children in urban areas. This is a normal age range of the mothers for giving birth to a healthy baby. But it is also seen that, in the rural areas a good number of cases (40.78%), immature mother gave birth of the mentally retarded children. Therefore, it is assumed that this lower age of the mothers can be considered as a factor for mental retardation.

The normal prenatal period is 10 lunar months or 9 calendar months in length. However, there is great variation in this length, ranging from 180 days, the shortest known time preceding the birth of a life fetus, to 334 days, the legal time of post maturity. There are approximately three times as many babies born prematurely as post maturely (Carmichael, 1954). In table 3.1.1. it is seen that 22.22% children were born prematurely in urban areas and 33.98% were born prematurely in rural areas. The large majority of the subjects were full time babies.

Since growth is most rapid during the period of the fetus, proteins are needed for the tissue building and repair, fats for the formation of fat tissues and fuel for the body, and carbohydrates for the strength and energy. If the mother suffers from serious malnutrition due to poverty, ignorance or proper diet, or war conditions, serious damage may be done to the fetus in the form of general physical weakness, rickets, nervous instability, or mental deficiency (Burke *et al.* 1949).

Malnourishment, as a single variable, is quite difficult to separate from generally poor prenatal care, poor sanitation and lack of adequate shelter. Nonetheless, it appears to have a deleterious effect on a developing embryo, or fetus (Dobbing, 1970).

Poor maternal health and nutrition contributes to low birth weight in 20 million babies each year almost 20% of all births. These babies die more often than babies of normal weight, and are at greater risk for infection, malnutrition and long term disabilities, including visual and hearing impairments, learning disabilities and mental retardation (Bellamy, 1998).

The findings related to maternal diet are shown in figure 3.1.1. of the preceding chapter and it is seen that the large majority rated their diet either as average, or above average. However, the trend found in the result indicates that the respondents have given their responses on their subjective frame of reference. It may be mentioned here that Bangladesh is a poverty stricken country and majority of the people generally live on poor diet. So these responses may not truly reflect the actual standard of the diet of the pregnant mothers. It is popularly believed that malnutrition is one of the major causes of retardation in this country. But the findings of the present study show that the distribution is normal. It is difficult to draw any definite conclusion from the result.

Serious illnesses of the mother during pregnancy are always considered as an important factor for mental retardation of the baby. In this study it was found that 9.72% urban mothers and 11.65% rural mothers had serious illnesses during pregnancy period of the subjects which is shown in table 3.1.2. Some of these mothers had to take antibiotics and relatively stronger medicine. However, since the percentage is very low, this factor is not considered as a general factor, but an important factor.

Until last decade many mentally retarded children died during their infancy and babyhood because of wrong treatment. This situation has improved to some extent since the decade of eighties of last century when some NGOs like SIVUS institute, SWID Bangladesh and BPF arranged countrywide seminars, discussions, etc. on mental retardation for the common people. These NGOs arranged some training courses for the village physicians, too. These awareness programs improved the situation.



During interview, the researcher understood that many parents did not take treatment initiatives for their mentally retarded children at all. In table 3.1.7(b), it was seen that Psychologists diagnosed not a single mentally retarded child in the rural areas.

The treatment administered to the subjects was shown in figure 3.1.3. The treatment given to them also included Faith healing, Ayurvedic and Homeopathy. These are cheaper, easily available and very common in Bangladesh. It is assumed that such treatments could not improve the condition. Rather in most cases these treatments jeopardized the overall condition.

It was found that many children were subjects of viral and bacterial infections. The researcher has seen many sick mentally retarded children living in careless and dirty environments practically without any treatment. It was seen that a large number of the mentally retarded children were attacked by very high fever at their early stages of lives. Diarrhea, Cough, Pneumonia and different types of infections attacked many of them.

Nature of treatment given to the mentally retarded children who were attacked by different diseases was presented in tables 3.1.11. to 3.1.14. of the previous chapter. It is seen from the data that in most cases, qualified physician did not treat them. In most cases village physicians including Ayurvedic and Homeopathic Physicians gave them the treatments. It was also found that in the rural areas there is a severe scarcity of graduated physicians. The paramedics and quack physicians who provide private treatments are not well educated and well trained. There are some trained village physicians in some areas but large majorities of the physicians have no training at all.

Through this study, the researcher has come to know that the number of the mentally retarded persons who take Psychotropic medicines regularly is few in number in urban areas (5.10%), whereas none of the mentally retarded persons take psychotropic medicines in rural areas [table 3.1.14(b)]. The researcher has seen many mentally retarded persons who have some physical problems too. The researcher assumes that it is possible to solve many of their physical problems with Physiotherapy, not by Chemotherapy.

From the findings of previous studies the researcher understood that there are about 200 causes of mental retardation in Bangladesh. But after analyzing the information given by the parents, guardians, neighbors, village physicians, etc. the researcher understood that high fever associated with convulsion, different viral attacks and severe infections during infancy and babyhood are important factors of mental retardation in the country. It is also understood that the roots of such diseases are mainly the difficult and defective births in the absence of trained midwives in the rural areas. Both in rural and urban areas the infants are born at their homes and large majority of them were born through trials and errors after prolonged labour pain of the mothers in the hands of neighboring women. Such births ultimately caused asphyxia or brain injury to the infants. Such births were mostly followed by meningitis including high fever associated with convulsion. And in most cases the diagnosis and treatment was wrong. The researcher also understood that many viral and bacterial diseases of the children are major causes of mental retardation in Bangladesh.

**Education:**

Bangladesh government declared primary education compulsory for all its citizen, some years ago. In reality it is seen that primary education is free in the government primary schools, but not compulsory. Secondly, yet there is no curriculum and education facilities for the mentally retarded children.

It is also assumed that at least 2 million mentally retarded children are in need of some special education in Bangladesh. Of these 2 million, approximately 80% live in the rural areas and yet there is no special education programme in the rural areas, even at private initiative.

In the absence of government programmes, at present three registered voluntary organizations are working for the mentally retarded persons in Bangladesh. These are Society Welfare for the Intellectually Disabled (SWID) Bangladesh, Bangladesh Protibandhi Foundation (BPF) and the SIVUS Institute. Approximately 3000 mentally retarded children and adults are affiliated with the day care programmes of these three organizations, mainly in urban areas. About 1% of the total mentally retarded population of Bangladesh is under their care programs. Remaining 99% are completely beyond any professional care and stimulation of any agency.

During 1988-1991 the Directorate of Social Welfare initiated drafting of a curriculum for the mentally retarded children. But yet there is no curriculum for the mentally retarded children approved by any ministry of the Government in Bangladesh. There is no national policy for the mentally retarded persons in this country. Therefore, all the agencies are doing trials and errors with the mentally retarded children in the name of their special education. The NGOs are mostly bringing children to some urban Day Centres and trying to give them some subject centred teaching. It could be better if these NGOs could give them child centred teaching.

The researcher observed that there are some special schools for the mentally retarded children in the urban areas only, which are mostly segregated day care centres, and not the integrated schools. Most of these special schools have their own curriculum and own philosophies according to the facilities available with the individual centre.

In some schools it is teacher centered education and in some schools it is the subject centered education, rarely it is child centered. However, the teachers try their best to help individual children.

It was found that many of the mentally retarded children who are subjects of this study were given admission to the normal schools. Most of them either dropped out or were ultimately sent back from the schools. The findings related to educational attempts and opinion of the guardians related to education of the subjects were shown in different tables from 3.2.1 to 3.2.10 of the preceding chapter.

Considering the existing special education programmes of the whole country, The researcher finds a very poor picture. In Bangladesh, yet the number of special education schools are not enough even in the Urban areas. In large majority of the towns, there is no special education school. It was mentioned earlier that yet 99% of the total mentally retarded population of the whole country are beyond any program or stimulation. And whatever the services are there, mostly the Day centers are situated only in the large cities. Therefore, special educations for the rural mentally retarded persons are far beyond imagination. What the rural mentally retarded children are learning are the contribution of their families.

It was mentioned earlier in many pages of this thesis that yet there is no National policy of the government for the mentally retarded persons. But the mentally retarded persons are not only the citizens of the country, they are also the taxpayers and voters. It is also the constitutional obligation of the Government to uplift the condition of the handicapped persons. But the Government did nothing in this country for their education. However, during last five years government paid 80% salary subsidy to the staff of two NGOs working for the mentally retarded children.

In 1990, in a National Seminar on Mental Retardation in Dhaka the NGOs working for the mentally Retarded persons proposed the Government that the special education of the mentally retarded persons should be integrated inside the government primary schools. It was proposed that in each government primary school, there should be one classroom for special education. The handicapped children will attend all common

programs of the school with other children and in education they will follow some special curriculum. Such integration could improve the way of socialization of the mentally retarded and non-retarded children. Secondly, such arrangements could promote general awareness. But nothing was done for the education of the mentally retarded children by the government.

It was mentioned earlier that practically nothing has been done to promote any Special education programme in the rural areas in Bangladesh. And the matters related to the education of the mentally retarded children in the rural areas depict the poorest picture all over the county. If we seriously consider the overall situation, the strength of the Government machinery, resources, etc. we find that it is not possible to immediately start special education classes in all primary schools at this moment. But model centres can be started on experimental basis. Though the concerned Government officers have started thinking this matter, yet the matter was not published in any newspaper. However, the researcher thinks that it will not be wise to start segregated special education schools for the mentally retarded children in rural areas at this moment. Because the life pattern of the rural people, the communication problems, motor disabilities of the handicapped children, etc. most of the mentally retarded children will not come to a segregated special school. The researcher thinks that home based special education program will be more helpful for the mentally retarded children. In this context the researcher strongly recommends Portage Programme.

The concept of Portage Program was briefly described in Literature Review section of Chapter-I of this thesis. In portage program generally the service involves a home teacher visiting an individual family at regular intervals, assessing the child periodically and deciding with the parent the appropriate activities to carry out with the child. In Portage system the home teacher has a resource of the activity cards linked to a developmental checklist. The teacher uses the cards to plan up to three or four instruction and recording sheets for the parents to follow and fill in during the week before the next visit. There are some standard Portage packages developed in English language. In many countries the Portage Programme is adopted in their own

languages. In Bangladesh, Dr. Sultana Zaman and her associates of the Protibandhi Foundation have developed and standardized the Bengali version of the package that is widely being used, mainly in the rural areas. There are some controversies related to the contents of the portage program. Some parents reported that the contents are more academic than vocational. The parents suggest further revision of the curriculum and contents of the portage program.

During her close discussion with the guardians, teachers and concerned professionals, the researcher understood that all of them feel that some special education is needed for the mentally retarded children. The guardians do not know much about the special education programs. They feel that the children at least should know the basic calculations and some easy vocational education. What they expect in relation to curriculum, places of special schools, promoters of such education, etc. are shown in different tables of the preceding chapter.

The concept, standard, service rendering, arrangement and implementation of special education depend on the socioeconomic condition of a country. In Bangladesh yet the government could not implement compulsory primary education for all the children. Therefore, implementation of special education for the mentally retarded children can not be expected within a short period. The researcher feels that it is the time when concerned professionals must try their best to give a practical plan to the government.

**Employment:**

It was mentioned earlier that previously the mentally retarded persons of this country had shorter life spans. Now they are living longer and many of them have started experiencing aging process like people of normal intelligence. Earlier, the employment and economic activities of the mentally retarded persons were not considered seriously by the families. Now the employment matters are seriously thought in all families. They may not become expert in all trades or works like general people. Yet if they are given the opportunity, they can participate in many financial activities. The researcher has found many mentally retarded persons who are already engaged in works. Some of them help their parents in agriculture, household, poultry and cattle rearing and so on. But most of them are jobless and loiter in the neighborhood. If necessary steps are taken it may be possible to engage them in many easy jobs.

Employment opportunity for the general population is yet very limited in Bangladesh. But there are many jobs that can be reserved for the mentally retarded persons. The jobs that do not need enough mental works are suitable for them. There can be a quota for the mentally retarded persons in the packaging units, security guard sections, etc. in the nationalized and public sector enterprises.

The researcher observed that in the rural areas, the employment sectors related to agriculture, poultry, dairy, etc. have already engaged some mentally retarded persons. But if some specialized vocational training can be given, the mentally retarded persons can also become skilled carpenters, repair workers, helping hands in shops, tea makers, food grain processors, handicraft manufacturers, etc. It is not necessary that a vocational training centre should be established to provide such trainings. The family members and friends can also help the mentally retarded persons to learn the necessary techniques. It is not necessary to set-up vocational training programs in rural areas for teaching, agriculture oriented jobs at this moment. The villagers themselves teach these activities to the mentally retarded persons. But in urban areas, where agriculture works are not possible, some specialized vocational training schools

for the mentally retarded persons are needed. Such specialized vocational training programs can be backed by sheltered workshops, too.

To promote job opportunities for the mentally retarded persons some mentally retarded persons can be grouped to perform special tasks or jobs. SIVUS group dynamic principles can be a good Philosophy towards employment of the mentally retarded persons. In relation to employment of the mentally retarded persons in Bangladesh, finally, the researcher concludes that unless there is a clear policy program of the government it is really impossible to create employment opportunities for them in this country. The small percentages of rural adult mentally retarded persons who are being absorbed in agriculture of their own abilities and easy living condition in rural life. But in urban areas unless the government and public enterprises are announcing quota for them it will not be possible to arrange jobs for them.

The goal of the SIVUS project is supporting the mentally retarded persons to function as independently as possible, both individually and socially, by considering every individuals ability, both within the area of provision and services for the mentally retarded and in the society in co-operation with others. The work methods used in SIVUS is characterized by actively taking part in co-operation with others, organized in small groups having fixed members, supervisors and the principal activity coming from the group member's mutual interests and functioning as democratically as possible, in other words through a social integration to achieve normalization. If 5-6 mentally retarded persons of different degrees of retardation and different levels of physical strengths are grouped together under the supervision of an able person, the group can cultivate land and do many other things together. Therefore, SIVUS group dynamic method can be an effective attempt towards employment of the mentally retarded persons in Bangladesh.



**Housing:**

During last 25 years, hundreds of seminars and symposiums were arranged in National level to discuss Mental Retardation. But housing issue of the mentally retarded persons was never raised or discussed. With the increase of the life span of the mentally retarded persons in Bangladesh, now a days the families are experiencing some problems with the residential accommodation matters of the adult mentally retarded persons. To see the reality of housing and living condition of the subjects the researcher visited the houses of all the subjects of this study. She found all the mentally retarded persons are living with the members of their families in the same house. Most of the mentally retarded persons do not have independent rooms. They live with some other member of the family sharing the rooms. But many mentally retarded children do not get enough care and opportunities like their normal siblings. A good number of parents/guardians do not have any plan to provide them more comfortable accommodation as they do for their normal children. In some families, other siblings were found do not like to live with the mentally retarded sibling in the same house. However, the housing matters of each case are different considering the socioeconomic condition of the families.

In Bangladesh yet there is no National Housing Policy for its citizen like the social welfare countries. Housing policy for the mentally retarded is far beyond imagination at this moment in Bangladesh. In Norway, it is a Government Policy that every adult mentally retarded person can get an independent apartment from the Government, if he or she is not living with the patents. Not only the apartment, Norwegian Government provide part time helping hands and some pension money to the mentally retarded persons for their independent living. Similar or near similar is the condition in Sweden, Finland and Denmark.

In Japan, both the central and local government are concerned with the housing of the mentally retarded children and adults. If the parents feel that they can't take appropriate care of their mentally retarded children at home, they can send them to government residential care homes. If there is no seat in government residential care

home, parents can get government financial support to send them to private residential institutions.

In The Netherlands, the adult mentally retarded persons live in Large Scale Residential Institutions, if the degree of retardation is severe. The staff members of these institutions take all care of the mentally retarded persons. In India there are many residential homes and Institutions of different levels both in private and public sectors.

The researcher observed that the housing problems of the middle class urban subjects are most severe compared to all other subjects. The problem is more acute in Dhaka city. In Dhaka city, large majorities of the mentally retarded persons of the middle class families practically remain confined inside small apartments. Secondly, those who are not affiliated with any Day Centre are completely confined inside their houses. In district level towns the mentally retarded persons may loiter at least in their neighbourhood.

Yet there is no residential institution for the mentally retarded persons in Bangladesh which are run by the Government. In private level, there are few residential institutions but not well known. Many parents/guardians feel that it has become necessary to establish some residential institutions, at least for short stay of the subjects when parents want to leave home in emergency. It was observed that many parents/ guardians could not leave home in emergency situation when they have a severely handicapped child. In such cases either of the parents stay at home to take care of the subjects.

In rural Bangladesh most of the families are yet joint families. In rural areas, the problems of the parents are relatively lesser compared to the urban parents. The parents/guardians usually do not face the problems to leave behind their handicapped children at home when they need to go to the towns or somewhere. Their close relatives look after the handicapped persons. The researcher also observed that the socialization processes of the rural mentally retarded persons are better compared to their urban counterparts. In rural areas the mentally retarded children get equal

opportunity to play in fields and involve in different social interactions like other children. Such opportunities develop them for adult life interactions, too.

Reviewing the chronological changes of housing matters of the mentally retarded persons in developed countries since Second World War, the researcher understood that the present housing status of the mentally retarded persons of the Bangladeshi subjects can be compared with the pre-industrial revolution housing status of the West European countries. Now the mentally retarded persons are living in their parental houses in the warmth of the families. But if any industrial revolution takes place in this country, they will loose this family warmth. They will be sent to residential institutions like West European countries, too. To avoid such situation now it is the time when the professionals must plan how the housing matters of the mentally retarded persons be dealt during next part of this century and it needs further discussion and detail study.

### **Social security:**

In this study some questions were asked to the guardians related to social security of the subjects. Some questions had given answers; some questions were answered spontaneously by the respondents themselves. The findings are shown in Table 3.5.1. to 3.5.9. in the preceding chapter. From the given answers it is understood that practically there is no social security for the mentally retarded persons in Bangladesh, if we consider and compare the concept of social security systems of the developed countries, the concept of social security is different in different countries. Bangladesh is not yet a social welfare state like the Scandinavian, Benelux, West European or North American countries. Though the constitution of Bangladesh gives guarantee of a quality life for the handicapped people but it is far away in reality. Yet Bangladesh Government could not announce any National Policy for its handicapped citizen. It is seen that 80% Bangladeshi people are living in rural area where The '*Samaz*' are more powerful than the Government. The *Samaz* leaders are the persons who also monitor and decide many aspects of the life of the handicapped people, in addition to the families. The *Samaz* system of Bangladesh is an ancient social system practiced in Indian sub-continent. Though there are many drawbacks in individual villages because of individual *Samaz* leaders, but in large majority cases the system proved beneficial for the mentally retarded persons.

In this study the parents/guardians gave some of their opinions related to the social security matters of the mentally retarded subjects, the researcher perceived that the parents/guardians now clearly know that they will have to take all responsibility of their handicapped family members. Now the Government is not sharing any of their burdens nor it is possible for the Government to share any responsibility. However, the parents/guardians expect that Government should help them to some extent. When the researcher asked what helps are needed from the government, the families could not explain well what exactly can be done from the government's end. They have many expectations but different families have different expectations. It was very difficult to generalize the expectations, too.

Awareness among common people related to mental retardation is an important factor for quality life of the mentally retarded persons. Yet many mentally retarded persons are humiliated, irritated and exploited in Bangladesh. The parents/guardians who have strong economic and social power in the society try their best to protect their children from different humiliation and exploitations. But the situations of the poor people are miserable. Practically there is no law to protect the poor mentally retarded persons from humiliation and neglect. However, the social leaders yet look into the matters and protect them from many harmful social situations.

It was found that the parents/guardians of the female mentally retarded persons are always worried that their girls may be sexually abused. The birth of a mentally retarded child in a family sometimes becomes a social stigma and the prospects of marriage of other siblings are jeopardized in many cases. The parents/guardians of the mentally retarded persons are the most concerned persons and they feel more for them than the others. The parents/guardians of the rural areas have given different opinions related to social security matters of the mentally retarded persons, which are shown in the preceding chapter of this thesis. It was not specially studied but the researcher understood that the perceptual span of the parents/guardians of rural areas are limited compared to the metropolitan cities of the country.

However, from the opinions given by the respondents it is understood that some monthly benefit scheme from the Government like old age pension and widow pension schemes for the handicapped people will definitely increase their status in the society and in the family. They will get more social acceptances in general. Such financial benefit schemes will also reduce some burdens of the parents/guardians. To explore financial source of the government to introduce such pension schemes the researcher talked to some economists of the country. They informed the researcher that Bangladesh Government possesses a fund known as 'Zakat Fund'. In the absence of appropriate policy program this fund is not being utilized properly. At this initial stage government can introduce the pension scheme with this fund, at least for the poor mentally retarded persons. If the scheme works well government can seek donations from rich people of the country particularly for this pension scheme for the mentally retarded persons.

But above all, the researcher feels that awareness programs about mental retardation using Government mass media needs to be strengthened first that common people become aware of the rights of the handicapped people in this country. If people are aware of mental retardation, rights and privileges of the mentally retarded persons, they will take care that mentally retarded persons are not deprived. SIVUS volunteers worked extensively in 'Auchpara Union' of Rajshahi District during 1992-2003. They visited all the houses of the entire union and explained the villagers about mental retardation. Now in these villages the common people look after the problems of the mentally retarded persons. Secondly, in these villages prevalence rate is also significantly reducing day by day. The village physicians are aware of all health hazards and birth hazards due to different awareness programs.

**Conclusion:**

Though this research was designed mainly to study the psycho-social correlates of mental retardation of some selected cases, the researcher also inquired the cases of the mentally retarded persons who died recently or few years ago inside the study areas. She was personally face to face with all the living mentally retarded persons, their parents, guardians, siblings, neighbors and local leaders. She discussed different aspects related to the subjects with the guardians and the family members. Considering her observation, informal and formal interviews and case studies, the researcher wants to conclude the following:

Health, education, employment, housing and social security of the mentally retarded persons are the most important psycho-social correlates of total life of these persons.

The problems related to health are the most serious problems of the mentally retarded persons as it is related to their life and death. Though the existing medical services provided by the government do not restrict the mentally retarded persons to avail all possible Government facilities, the distance and the communication problems are yet the strongest barriers in rural areas. The situation is better in the urban areas. However, the situation is also improving in the rural areas, too.

In Bangladesh it takes relatively longer time for the parents to know that their children are mentally retarded. They usually come to know the reality of the subjects during childhood of the subjects. Meanwhile, the parents attempt many so-called treatments that jeopardize the health of the subjects. In many cases it was found that the treatments provided were faulty treatments. As the mentally retarded persons can not communicate their real physiological problems to their guardians and physicians, they depend on the perception of others.

Defective births through trials and errors in the absence of qualified medical professionals and trained midwives are one of the most important causes of mental retardation in Bangladesh. Illnesses of the pregnant mothers and indiscriminate use of medicine is another important factor. The situation is slightly better in the urban areas.

Almost all the subjects of the rural areas are free from psychotropic drugs and an opposite situation was found in the urban areas.

It was found that large majorities of the mentally retarded subjects were enrolled in the primary schools but finally dropped out. Special Education opportunity is practically nil in the rural areas. But parents possess very high positive attitude towards special education. Yet there is no national curriculum for special education of the mentally retarded children in Bangladesh and the concerned agencies are yet doing some trials and errors with the children.

In Bangladesh, the rural people possess positive attitude to employ the adult mentally retarded persons in easy works. Now the mild and moderately retarded adults, both male and female, are mostly engaged in agriculture oriented jobs in the rural areas. If some vocational training can be given to them, the employment scope will definitely increase. On the other hand, the employment opportunities of the urban mentally retarded persons are yet very low and needs some interventions from the government.

In general, the housing conditions of the subjects are not different from their siblings and other members of their families. There are acute problems with the severely handicapped persons and the parents can't leave them alone at home.

The social security matters are not up to the mark, but the subjects were found well integrated in their own families and societies in rural areas compared to the urban mentally retarded persons. The families expect some financial support from the government.



### **Recommendations:**

The researcher recommends the following to improve the quality of life of the mentally retarded persons in Bangladesh.

It is the time when the people and the government in Bangladesh must realize that the mentally retarded persons are also the taxpayers and voters of this country. But they are not being given enough care by the government that is also protected and ensured by the Constitution of Bangladesh. Now it has become essential that government should announce a Policy Program for the mentally retarded persons of the country. The proposed policy program must include issues of their health, education, employment, housing and social security.

To prevent birth of mentally retarded children in Bangladesh the Traditional Birth Attendants (TBA) living in the rural areas need some training from qualified medical personnel. It is also necessary that at least one trained midwives are appointed by the government in every village or at least for two villages in the rural areas.

Until the graduate medical physicians are not being easily available, some short courses can be arranged by the Health Directorate in every union for the rural physicians to improve their quality of services. Some control is also needed on the indiscriminate use of drugs including homeopathic and ayurvedic drugs. Care should be taken that pregnant mothers are not given indiscriminate medicines.

Mentally retarded children have the constitutional rights to get some special education and the government should immediately include special education classes in all the Government Primary Schools. The mentally retarded children should take part in all the common activities of the schools and follow special curriculum inside a separate room during class hours. It will be unwise to encourage NGOs to set up segregated Day Centres for the handicapped children in the country, especially in the rural areas.

It has become essential that the government must introduce some monthly pension scheme for the handicapped persons in the country like the old age pension scheme and widow allowances. Introduction of such financial support schemes will obviously help the families. Thus the social status of the handicapped persons will increase significantly. Such schemes, whatever the amount is, will bring tremendous awareness among the citizen towards the mentally retarded persons in the country, too.

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# Appendices

# Appendices

## Appendix - I

ছবি

### Questionnaire (The Bengali version)

প্রতিবন্ধীর সাধারণ পরিচয়

নাম : -----

জন্ম তারিখ : ----- বয়স : ----- লিঙ্গ : -----

ঠিকানা : -----

পিতার নাম : -----

বয়স : ----- পেশা : ----- বাৎসরিক আয় : -----

শিক্ষাগত যোগ্যতা : -----

মাতার নাম : -----

বয়স : ----- পেশা : ----- বাৎসরিক আয় : -----

শিক্ষাগত যোগ্যতা : -----

মোট সন্তান সংখ্যা : ----- প্রতিবন্ধী কততম সন্তান : -----

প্রতিবন্ধী শিশু যদি পিতা-মাতার সাথে বসবাস না করে সে ক্ষেত্রে যার সঙ্গে বসবাস করে তার নাম, ঠিকানা ও সম্পর্ক : -----

প্রতিবন্ধকতার ধরন :

স্তর ভিত্তিক	চিকিৎসামূলক
১. সীমারেখা	১. ডাউস সিনড্রোম
২. মৃদু প্রতিবন্ধী	২. ক্রেনিয়াল এ্যানোমলিস
৩. মধ্যম প্রতিবন্ধী	২.১ হাইড্রোসেফালী
৪. গুরুতর প্রতিবন্ধী	২.২ মাইক্রোসেফালী
৫. চরম প্রতিবন্ধী	৩. ক্রেটিনিজম
	৪. পি,কে,ইউ
	৫. তেজস্ক্রিয় প্রতিক্রিয়া

## প্রতিবন্ধীর বর্তমান অবস্থা

(নির্দিষ্ট ঘরে (✓) চিহ্ন দিন)

আচরণগত অবস্থা	প্রতিক্রিয়ার মাত্রা					মন্তব্য
	খুব ভাল	শাল	মোটামুটি	খারাপ	খুবখারাপ	
টয়লেট ট্রেনিং						
পোষাক পরিধান ক্ষমতা						
খাবার নিজে খেতে পারার ক্ষমতা						
বসা						
দাঁড়ানো						
হাঁটা						
শব্দ উচ্চারণ এবং কথা						
শ্রবণ শক্তি						
স্রাবণ শক্তি						
স্বাদ সংবেদন						
ত্বক সংবেদন (ঠাণ্ডা, গরম, চাপ, ব্যথা)						
কোন নির্দেশ বুঝতে পারার ক্ষমতা						
সাধারণ শারীরিক গঠন						
বুদ্ধি						
স্মৃতি শক্তি						
চঞ্চলতা						
স্বাভাবিক বুদ্ধিও সমবয়সীদের তুলনায় সাধারণ জ্ঞান						
স্কুলের সামগ্রিক আচরণ						
বাড়ীতে সামগ্রিক আচরণ						
সামাজিক প্রেক্ষাপটে সামগ্রিক আচরণ						
খেলা-ধুলার সময় আচরণ						
রাত্তাঘাটে চলার সময় আচরণ						
বাড়ীতে অতিথি এলে আচরণ						
অন্য আত্মীয়ের বাড়ীতে গেলে আচরণ						
বাজারে/দোকান পাটে নিয়ে গেলে আচরণ						
শিক্ষকদের সাথে আচরণ						
বাবা-মার সাথে আচরণ						
ভাই-বোনদের সাথে আচরণ						
পরিচিতজনদের সাথে আচরণ						
অপরিচিতজনদের সাথে আচরণ						
চিকিৎসকের / কাউন্সেলর এর সাথে আচরণ						
সমবয়সীদের সাথে আচরণ						
পরিষ্কার পরিচ্ছন্নতা						

**ଅଭିବକ୍ତିର ସାମ୍ପାଦକୀୟ ସମ୍ପାଦିତ ତଥ୍ୟ**

ଉପର ନୀଚାଂଶିକା / ଯାତା / ତାହା-ହା-ବେନ / ଅନ୍ୟ କେନ ଆକ୍ରାନ୍ତ

୧. ଆମାମୀର ସଞ୍ଚାଳନର କତ ବଜ୍ର ବସନେ ଶୋଭା ଦେବାପାଇଁ ପାଠକମାନେ ଯେ, ସେ ଅଭିବକ୍ତି ?

କିଭଳିଏ ବୁଝାଉଣେ ଯେ, ସେ ଅଭିବକ୍ତି ?

କ) ସ୍ତ୍ରୀ ଶାନ୍ତିର ସାମାଜିକ ବିକାଶ

ଖ) ସାମାଜିକ ସମ୍ପୂର୍ଣ୍ଣତା ବିସ୍ତାରଣର ଉଦ୍ଦେଶ୍ୟ

ଗ) ଶକ୍ତିଶାଳୀର ଅନ୍ୟ ଉଦ୍ଦେଶ୍ୟ ଯାହାକି ଉପର ବାସ୍ତବିକ କରାଯାଏ ନା

ଘ) ଉପରୋକ୍ତ ସମସ୍ତେ ଅନ୍ୟ କିଛି କିଛି ନିମ୍ନରେ ନା ପାରିବ (ଯେମାନେ, ଯାହାକି, ଉପରୋକ୍ତ ହେଉଛି, ଉପରୋକ୍ତ ହେଉଛି, ଉପରୋକ୍ତ ହେଉଛି)

୨. ବିଭିନ୍ନ ସମୟରେ ଅଭିବକ୍ତିର ଜଣା କି ଚିକିତ୍ସା କରାଯାଇଛି ?

ଚିକିତ୍ସାର ସମୟ					ସମୟ
ସାମାଜିକ ଚିକିତ୍ସା	ଅନ୍ୟାନ୍ୟାନ୍ୟ	କୋମ୍ୟୁନିଟି	କାରିଗରୀ	ସାମାଜିକ	ଜଣା - ୧୪ ମିନ
					୧୫ ମିନ ୨ ବସନ
					୨ ବସନ - ୧ ବସନ
					୧ ବସନ - ୧୨ ବସନ
					୧୨ ବସନ - ୧୪ ବସନ
					୧୪ ବସନ - ୧୫ ବସନ
					୧୫ ବସନ - ୧୬ ବସନ
					୧୬ ବସନ - ୧୭ ବସନ
					୧୭ ବସନ - ୧୮ ବସନ
					୧୮ ବସନ - ୧୯ ବସନ
					୧୯ ବସନ - ୨୦ ବସନ

୩. ଅଭିବକ୍ତିର ଉଦ୍ଦେଶ୍ୟ ଉପରୋକ୍ତ ବିବରଣୀ :

ସମୟ	ଉଦ୍ଦେଶ୍ୟ ବିବରଣୀ	ସମ୍ପୂର୍ଣ୍ଣତା ବିବରଣୀ
ଜଣା - ୧୪ ମିନ		
୧୫ ମିନ ୨ ବସନ		
୨ ବସନ - ୧ ବସନ		
୧ ବସନ - ୧୨ ବସନ		
୧୨ ବସନ - ୧୪ ବସନ		
୧୪ ବସନ - ୧୫ ବସନ		
୧୫ ବସନ - ୧୬ ବସନ		
୧୬ ବସନ - ୧୭ ବସନ		
୧୭ ବସନ - ୧୮ ବସନ		
୧୮ ବସନ - ୧୯ ବସନ		
୧୯ ବସନ - ୨୦ ବସନ		

୪. ବର୍ତ୍ତମାନେ କି ଚିକିତ୍ସା କରାଯାଉଛି ?

- କ) କୋମ୍ୟୁନିଟି କାରିଗରୀ (୧) କାରିଗରୀ (୨) କାରିଗରୀ (୩) କାରିଗରୀ (୪) କାରିଗରୀ (୫) କାରିଗରୀ (୬) କାରିଗରୀ (୭) କାରିଗରୀ (୮) କାରିଗରୀ (୯) କାରିଗରୀ (୧୦) କାରିଗରୀ (୧୧) କାରିଗରୀ (୧୨) କାରିଗରୀ (୧୩) କାରିଗରୀ (୧୪) କାରିଗରୀ (୧୫) କାରିଗରୀ (୧୬) କାରିଗରୀ (୧୭) କାରିଗରୀ (୧୮) କାରିଗରୀ (୧୯) କାରିଗରୀ (୨୦) କାରିଗରୀ (୨୧) କାରିଗରୀ (୨୨) କାରିଗରୀ (୨୩) କାରିଗରୀ (୨୪) କାରିଗରୀ (୨୫) କାରିଗରୀ (୨୬) କାରିଗରୀ (୨୭) କାରିଗରୀ (୨୮) କାରିଗରୀ (୨୯) କାରିଗରୀ (୩୦) କାରିଗରୀ (୩୧) କାରିଗରୀ (୩୨) କାରିଗରୀ (୩୩) କାରିଗରୀ (୩୪) କାରିଗରୀ (୩୫) କାରିଗରୀ (୩୬) କାରିଗରୀ (୩୭) କାରିଗରୀ (୩୮) କାରିଗରୀ (୩୯) କାରିଗରୀ (୪୦) କାରିଗରୀ (୪୧) କାରିଗରୀ (୪୨) କାରିଗରୀ (୪୩) କାରିଗରୀ (୪୪) କାରିଗରୀ (୪୫) କାରିଗରୀ (୪୬) କାରିଗରୀ (୪୭) କାରିଗରୀ (୪୮) କାରିଗରୀ (୪୯) କାରିଗରୀ (୫୦) କାରିଗରୀ (୫୧) କାରିଗରୀ (୫୨) କାରିଗରୀ (୫୩) କାରିଗରୀ (୫୪) କାରିଗରୀ (୫୫) କାରିଗରୀ (୫୬) କାରିଗରୀ (୫୭) କାରିଗରୀ (୫୮) କାରିଗରୀ (୫୯) କାରିଗରୀ (୬୦) କାରିଗରୀ (୬୧) କାରିଗରୀ (୬୨) କାରିଗରୀ (୬୩) କାରିଗରୀ (୬୪) କାରିଗରୀ (୬୫) କାରିଗରୀ (୬୬) କାରିଗରୀ (୬୭) କାରିଗରୀ (୬୮) କାରିଗରୀ (୬୯) କାରିଗରୀ (୭୦) କାରିଗରୀ (୭୧) କାରିଗରୀ (୭୨) କାରିଗରୀ (୭୩) କାରିଗରୀ (୭୪) କାରିଗରୀ (୭୫) କାରିଗରୀ (୭୬) କାରିଗରୀ (୭୭) କାରିଗରୀ (୭୮) କାରିଗରୀ (୭୯) କାରିଗରୀ (୮୦) କାରିଗରୀ (୮୧) କାରିଗରୀ (୮୨) କାରିଗରୀ (୮୩) କାରିଗରୀ (୮୪) କାରିଗରୀ (୮୫) କାରିଗରୀ (୮୬) କାରିଗରୀ (୮୭) କାରିଗରୀ (୮୮) କାରିଗରୀ (୮୯) କାରିଗରୀ (୯୦) କାରିଗରୀ (୯୧) କାରିଗରୀ (୯୨) କାରିଗରୀ (୯୩) କାରିଗରୀ (୯୪) କାରିଗରୀ (୯୫) କାରିଗରୀ (୯୬) କାରିଗରୀ (୯୭) କାରିଗରୀ (୯୮) କାରିଗରୀ (୯୯) କାରିଗରୀ (୧୦୦)

৫. চিকিৎসকের প্রয়োজন হলে কত দূর যেতে হয় ?

চিকিৎসকের ধরন	দূরত্ব
এমবিবিএস	
প্যারামেডিক	
পল্লীচিকিৎসক	
হোমিওপ্যাথী	

৬. প্রয়োজনীয় ঔষধ পথ্য কেনার সামর্থ্য আছে কি না ?

ক) পুরোপুরি সামর্থ্য আছে খ) সামর্থ্য আছে গ) মোটামুটি সামর্থ্য আছে ঘ) সামর্থ্য নেই ঙ) একটুও সামর্থ্য নেই

৭. আপনি কি মনে করেন যে, চিকিৎসা করলে আপনার সন্তান ভাল হয়ে যাবে এবং অন্যান্য শিশুর মত বুদ্ধিমান হবে, প্রাইমারী পাশ করতে পারবে ?

ক) সম্পূর্ণরূপে ভাল হবে এবং খুব ভালভাবে প্রাইমারী পাশ করতে পারবে

খ) ভাল হবে এবং প্রাইমারী পাশ করতে পারবে

গ) কিছুটা ভাল হবে এবং কোন রকমে প্রাইমারী পাশ করতে পারবে

ঘ) ভাল হবে না এবং প্রাইমারী পাশ করতে পারবে না

ঙ) একটুও ভাল হবে না এবং কোন ভাবেই প্রাইমারী পাশ করতে পারবে না।

৮. আপনার সন্তানকে কি এখন নিয়মিত প্রতিদিনই কোন ঔষধ খাওয়াতে হয় ? হ্যাঁ / না

৯. প্রতিবন্ধীর শারীরিক কোন সমস্যা আছে কি ? হ্যাঁ / না

যদি কোন সমস্যা থাকে তার বিবরণ : -----

১০. প্রতিবন্ধীকে দেখাশোনা করে কে ? (যদি সম্পূর্ণরূপে অন্যের উপর নির্ভরশীল হয়) -----

১১. কি কি বিষয়ে দেখাশোনা / নার্সিং প্রয়োজন ? -----

১২. গর্ভকালীন সময়ের বিস্তৃতি কত ছিল? (Prenatal duration)

১৩. মায়ের গর্ভকালীন সময়ে তার খাবার কেমন ছিল?

খুব ভাল / ভাল / মোটামুটি / খারাপ / খুব খারাপ

১৪. গর্ভকালীন সময়ে মায়ের কি মারাত্মক কোন রোগ বা অসুখ হয়েছিল? হ্যাঁ / না

১৫. গর্ভকালীন সময়ে মা কি সব সময় দুশ্চিন্তা গ্রস্থ ছিল? হ্যাঁ / না

১৬. গর্ভকালীন সময়ে মায়ের নিয়মিত শারীরিক Check-up করানো হত কি? হ্যাঁ / না

১৭. Labour pain এর Duration কত সময় ছিল?

১৮. প্রতিবন্ধীর জনের প্রক্রিয়া:

ক) স্বাভাবিক

খ) সিজারিয়ান

গ) অন্যান্য

প্রতিবন্ধীর শিক্ষা সম্পর্কিত তথ্য

১. শিশুটি কি কখনও স্কুলে গিয়েছে? হ্যাঁ / না
২. শিশুটি কতদিনে স্কুলে গিয়েছিল? -----
৩. স্কুলে ভর্তির সময়ে কোন সমস্যা হয়েছিল কি? হ্যাঁ / না
৪. কি সমস্যা হয়েছিল? -----
৫. বর্তমানে স্কুলে যায় কি? হ্যাঁ / না
৬. কি কারণে স্কুলে যায় না?
- ক) স্কুলের পড়ালেখা আয়ত্ত্ব করতে পারে না      খ) স্কুলের অন্যান্য শিশুরা তাকে বিরক্ত করে
- গ) স্কুলের শিক্ষকরা নিষেধ করেছে      ঘ) অন্য কোন কারণ -----
৭. বাড়িতে তাকে লেখাপড়া শেখাতে চেষ্টা করেছেন কি? হ্যাঁ / না
- কিভাবে চেষ্টা করেছেন? -----
৮. তার লেখাপড়ার ব্যাপারে শিক্ষক বা অন্য কারও পরামর্শ নিয়েছেন কি? হ্যাঁ / না
- তারা আপনাকে কি পরামর্শ দিয়েছে? -----
৯. আপনার এলাকাতে মানসিক প্রতিবন্ধীদের জন্য কোন বিশেষ শিক্ষা ব্যবস্থা আছে কি? হ্যাঁ / না
১০. স্কুলে শিশু কিভাবে যাবে / আসবে?
- ক) নিজে নিজে হেঁটে      খ) সাইকেলে করে কেউ পৌঁছে দিয়ে আসবে
- গ) ভ্যানে অন্যদের সাথে      ঘ) কোলে চড়ে যাবে
- ঙ) অন্যভাবে -----
১১. আপনি কি মনে করেন যে, প্রতিবন্ধীদের জন্য বিশেষ শিক্ষার ব্যবস্থা থাকা প্রয়োজন? হ্যাঁ / না
১২. কি ধরনের শিক্ষা ব্যবস্থা থাকা প্রয়োজন? -----
- পাঠ্যসূচী কি হওয়া প্রয়োজন? -----
১৩. এ ধরনের শিক্ষা ব্যবস্থা কে চালু করবে?
- ক) সরকার      খ) ইউনিয়ন পরিষদ      গ) এন.জি.ও      ঘ) গ্রামের সব প্রতিবন্ধীদের পরিবারের পক্ষ থেকে
- ঙ) অন্যকেউ (কে?) -----
১৪. বিশেষ শিক্ষা ব্যবস্থা কোথায় চালু করবে?
- ক) সাধারণ স্কুলের সঙ্গে      খ) পৃথক স্কুলে      গ) প্রতিবন্ধীর বাড়িতে
- ঘ) অন্য কোথাও (বর্ণনা করুন) -----

### প্রতিবন্ধীর কর্মসংস্থান সম্পর্কিত তথ্য

১. আপনার প্রতিবন্ধী সন্তান কোন কাজ করতে পারে কি ? হ্যাঁ / না  
কি কাজ করতে পারে ? -----
২. আপনার প্রতিবন্ধী সন্তানকে স্বাভাবিক করার কোন পদক্ষেপ আপনার পরিবার থেকে নিয়েছেন কি ? হ্যাঁ / না  
কি পদক্ষেপ নিয়েছেন ? -----
৩. আপনার এলাকায় আপনার প্রতিবন্ধী সন্তানের কোন কর্মসংস্থানের সুযোগ আছে কি ? হ্যাঁ / না  
কি সুযোগ আছে ? -----
৪. সে কি কোথাও কর্মরত ? হ্যাঁ / না  
কোথায় ? -----
৫. কোন কর্মরত নয় ?  
ক) কাজ করতে অক্ষম খ) কাজের সুযোগ নেই গ) কেউ কাজে নেয় না  
ঘ) কাজ করার বয়স হয়নি ঙ) অন্য কোন কারণে -----
৬. তাকে কর্মসংস্থানের সুযোগ দিতে কি কি করতে হবে ? -----
৭. কে এই সুযোগ সৃষ্টি করবে ? -----  
কিভাবে করবে ? -----
৮. প্রতিবন্ধীকে কোন বৃত্তিমূলক প্রশিক্ষণ দিলে ভাল হয় ?  
ক) কৃষি কাজে খ) কার্টের কাজে গ) গৃহ কর্মে ঘ) পোলাট্রি  
ঙ) পারিবারিক ব্যবসায় চ) ডেয়ারী ছ) হস্ত শিল্পে জ) বাসার সাথে ছোট দোকান  
ঝ) অন্য কোন কাজ -----
৯. আপনি কি মনে করেন প্রতিবন্ধীদের সাধ্যানুসারে যে কোন একটি কর্মে অংশ গ্রহণ প্রয়োজন ? হ্যাঁ / না  
কোন ? -----
১০. আপনার প্রতিবন্ধী সন্তান সরকার বা কোন সংস্থা থেকে ভাতা পায় কি ? হ্যাঁ / না  
যদি অন্য কোন সাহায্য সহযোগিতা পায় তার বিবরণ : -----



### প্রতিবন্ধীর বাসস্থান সম্পর্কিত তথ্য

১. আপনার প্রতিবন্ধী সন্তানকে পৃথকভাবে রাখেন না অন্যান্য সন্তানদের সাথে একত্রে রাখেন ?  
ক) একত্রে      খ) পৃথকভাবে (কোথায়?) -----
২. প্রতিবন্ধী সন্তানের থাকার জন্য নির্দিষ্ট ঘর আছে কি ?      হ্যাঁ / না  
সে যে ঘরে থাকে সেটি কোথায় ?  
ক) একই বাড়ির ভিতর সবার সাথে      খ) তার জন্য পৃথকভাবে তৈরী ঘর
৩. প্রতিবন্ধী যে বাড়িতে বসবাস করে তার ধরন :  
ক) পাকা বাড়ি (মেঝে, ছাদ RCC)      খ) মাটির ঘর খড়ের ছাদ  
গ) মাটির ঘর টিনের ছাদ      ঘ) পাকা মেঝে ও দেয়াল এবং ছাদ টিনের  
ঙ) ঝুপরি  
সে কোথায় ঘুমায় ?      ক) মেঝেতে      খ) খাট বা চৌকিতে
৪. তার থাকার ঘর কে পরিষ্কার করে ?      ক) সে নিজেই করে      খ) অন্য কেউ ( মা / কর্মচারী )
৫. বাড়িতে তার যথেষ্ট সুযোগ সুবিধা না থাকায় সে কি প্রায়ই যেখানে সেখানে রাত কাটায় ?  
ক) হ্যাঁ (কোথায়?) -----      খ) না
৬. আপনার প্রতিবন্ধী সন্তানের পোষাক কি কি আছে ? -----  
ঐ পোষাক কি বাইরের অনুষ্ঠানে যাবার সময় পরিবারের অন্যান্য সদস্যদের সমমানের ?      হ্যাঁ / না  
প্রতিবন্ধীকে কি পরিবারের অন্যান্য সদস্যদের সমমানের খাবার দেওয়া হয় ?      হ্যাঁ / না
৭. আপনার মতে প্রতিবন্ধীদের বসবাসের জন্য উপযুক্ত স্থান কোনটি ?  
ক) নিজ পরিবারে      খ) গ্রুপ হোমে      গ) অন্য কোথাও -----
৮. পরিবারের অন্যান্য সদস্যরা তার সঙ্গে একই বাড়িতে থাকতে আগ্রহী কি ?  
ক) হ্যাঁ      খ) না (কেন ?) -----
৯. আপনাদের অবর্তমানে সে কোথায় থাকবে ?  
ক) এখন যেখানে থাকে সেখানেই      খ) পৃথক বাড়ির ব্যবস্থা আছে  
গ) অন্য কোথাও (কোথায়?) -----      ঘ) জানা নেই
১০. প্রতিবন্ধীর বসবাসের আরও সুবিধার জন্য কি কি করা প্রয়োজন ? কিভাবে তা করা সম্ভব ?  
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## সামাজিক নিরাপত্তা সম্পর্কিত তথ্য

১. আপনার সন্তানের সমস্যার কথা অন্যদের জানতে দেন কি ?  
ক) হ্যাঁ খ) না (কেন?) -----
২. আপনার প্রতিবন্ধী সন্তানের সাথে অন্যরা কিরূপ আচরণ করে ?  
ক) স্বাভাবিক আচরণ করে খ) বিরক্ত করে গ) শারীরিক নির্যাতন করে ঘ) এড়িয়ে চলে  
ঙ) অন্য কোন কিছু : -----
৩. কোন আত্মীয়ের বাড়িতে বেড়াতে বা কোন অনুষ্ঠানে আপনারা তাকে সাথে নেন কি ?  
ক) হ্যাঁ খ) না (কেন নেননা?) -----
৪. আপনি কি মনে করেন যে, প্রতিবন্ধীদের নিজ পরিবারের সাথে বসবাস করা উচিত ?  
ক) হ্যাঁ খ) না (কেন?) -----
৫. প্রতিবন্ধীদের ভরণ-পোষণের দায়িত্ব কার নেওয়া উচিত ?  
ক) পরিবারের সদস্যদের খ) সরকারের গ) এন.জি.ও গুলোর  
ঘ) অন্য কারও (বর্ণনা করুন) -----
৬. প্রতিবন্ধীর জন্য সরকারী ভাতা দেওয়া আবশ্যিক মনে করেন কি ? হ্যাঁ / না  
কেন? -----
৭. আপনার সন্তান প্রতিবন্ধী হওয়ার কারণে সামাজিকভাবে আপনি কি কি সমস্যার সম্মুখীন হন ?  
(বর্ণনা করুন) -----
৮. হারিয়ে যাওয়ার ভয়ে তাকে বেঁপে রাখেন কি ? হ্যাঁ / না  
প্রতিবন্ধী সন্তান কি অন্যান্যদের মত সামাজিক মেলামেশা, খেলাধুলা বা বিনোদনের সুযোগ পায় ?  
ক) হ্যাঁ খ) না (কেন?) -----
৯. প্রতিবন্ধী সন্তান মেয়ে হওয়ার কারণে তার কি কি সমস্যা আছে ?  
কি কি বিষয় নিয়ে আপনারা চিন্তিত ? -----
১০. সমাজের অন্যান্যদের মত স্বাভাবিক জীবন যাপনের জন্য প্রতিবন্ধীদের কি কি সুযোগ সুবিধা সৃষ্টি করা প্রয়োজন?  
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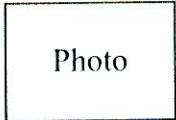
## সাধারণ প্রশ্ন

১. আপনার পরিবার যৌথ না একক ?                      ক) যৌথ পরিবার                      খ) একক পরিবার
২. আপনার পরিবারে মোট সদস্য সংখ্যা কত জন ? -----  
 কতজন আয় করে ? -----  
 সকলের সম্মিলিত বাৎসরিক আয় কত ? -----
৩. আপনার প্রতিবন্ধী সন্তানকে বিয়ে করাবেন কিনা ? (যদি না হয়ে থাকে)  
 ক) হ্যাঁ (কিভাবে করাবেন ? কেন করাবেন ?) -----  
 খ) না (কেন?) -----
৪. সন্তান প্রতিবন্ধী হওয়ার কারণে আপনাদের পরিবারিক জীবনে কি কি সমস্যা হয় ? -----
৫. গর্ভকালীন / প্রসবকালীন সময়ে কোন সমস্যা হয়েছিল কি ?                      হ্যাঁ / না  
 কি সমস্যা হয়েছিল ? -----
৬. প্রতিবন্ধী সন্তান জন্মকালীন সময়ে আপনাদের (স্বামী / স্ত্রী) বয়স কত ছিল ?  
 ক) স্বামী -----                      খ) স্ত্রী -----
৭. আপনারা কি স্বামী - স্ত্রী পূর্বেই রক্তের সম্পর্কে আত্মীয় ছিলেন ?                      হ্যাঁ / না  
 কি রকম আত্মীয়তা ? -----
৮. কি কারণে আপনার সন্তান প্রতিবন্ধী হয়েছে বলে মনে করেন ? -----
৯. আগামী ১০ বছর পর প্রতিবন্ধীর ভবিষ্যৎ কি হবে বলে মনে করেন ? -----
১০. পরিবারে বা আত্মীয়দের মধ্যে এরূপ সমস্যা অন্য কারও আছে কি ?                      হ্যাঁ / না  
 কার আছে ? ঠিকানা : -----  
 প্রতিবন্ধী সম্পর্কে গবেষকের নিজস্ব পর্যবেক্ষণ ভিত্তিক মন্তব্য : -----  
 -----

## Appendix – II

### Questionnaire (The English translation)

#### General Information of the Mentally Retarded Person



Name: -----

Date of Birth: ----- Age: ----- Sex: -----

Address: -----

Father's Name: -----

Age: ----- Occupation: ----- Yearly Income: -----

Educational Qualification: -----

Mother's Name: -----

Age: ----- Occupation: ----- Yearly Income: -----

Educational Qualification: -----

Number of Total Children: -----

Rank order of the mentally retarded child in siblings.....

In the case of retarded child not living with his/her parents, the guardian's name, address and relation with him/her: -----

**Categories of retardation:**

According to Degree	Clinical Type
1. Borderline	1. Down's Syndrome
2. Mild	2. Cranial Anomalies
3. Moderate	2.1 Hydrocephaly
4. Severe	2.2 Microcephaly
5. Profound	3. Cretinism
	4. Phenylketonuria (PKU)
	5. Ionizing radiation

### Behaviour checklist of the Mentally Retarded Person

(Put a tick (✓) in appropriate cell)

Level of functioning	Degree of reaction					Remarks
	Very Good	Good	Average	Poor	Very Poor	
Toilet Training						
Dress wearing ability						
Ability of self eating						
Seating						
Standing						
Walking						
Speaking						
Auditory sensation						
Visual sensation						
Olfactory sensation						
Gustatory sensation						
Skin sensation (Cold, Warmth, Pressure, Pain)						
Perceptual ability to follow instructions						
Physical Structure						
Intelligence						
Memory						
Motor activity						
General knowledge considering age group						
Behaviour at school						
Behaviour at home						
Social behaviour						
Behaviour at playing						
Behaviour at roads						
Behaviour at guest's arrival						
Behaviour at relative's house						
Behaviour in the market						
Behaviour with teachers						
Behaviour with parents						
Behaviour with siblings						
Behaviour with the known people						
Behaviour with the unknown people						
Behaviour with Physicians / Counselors						
Behaviour with the Friends						
Cleanliness						

**Information about the Health of the Mentally Retarded Person**

Respondent: Father / Mother / Sister-brother / other relatives

1. At what age of your child you come to know that he/she is retarded? -----

How did you come to know that your child is retarded?

- a) Slow mental development      b) Lack of social adjustment
- c) Inability to do school tasks      d) Inability to perceive problems
- e) Inability to use the limbs of the body
- f) Inability to learn proper things at proper age (such as, crawling, kneeling, walking etc.)

2. Treatment Given to the subject at different ages:

Age	Type of treatment				
	Faith healing	Ayurvedic	Homeopathy	Allopathy	Psychiatry
Birth – 14 days					
15 days – 2 years					
2 years – 6 years					
6 years – 12 years					
12 years – 14 years					
14 years – 17 years					
17 years – 21 years					
21 years – 40 years					

3. Description of the Major Illness of the Retarded:

Age	Description of Major illnesses	Description of Minor illnesses
Birth – 14 days		
15 days – 2 years		
2 years – 6 years		
6 years – 12 years		
12 years – 14 years		
14 years – 17 years		
17 years – 21 years		
21 years – 40 years		

4. What Kind of Treatment is being given now?

- a) Allopathy    b) Homeopathy    c) Ayurvedic    d) Mental treatment (Graduate Psychiatrist)

e) Others (Describe) -----

5. Distance from home to treatment providers?

Type of the physician	Distance
M.B.B.S	
Paramedic	
Village physician	
Homeopathy	
Others	

6. Ability level to buy treatment and medicine?

- a) Fully capable    b) Capable    c) Moderate ability    d) Unable  
 e) Fully unable.

7. Do you think that your child will be cured and intelligent enough like other children after treatment?

- a) Will be fully cured.  
 b) Will be cured.  
 c) Will moderately improve.  
 d) Will not be cured.  
 e) Will not be cured at all.

8. Is your Child now taking some Medicine Daily?                      Yes / No

If yes, what? -----

9. Has the Retarded Person possesses any Physical Problem?                      Yes / No

If any, please describe: -----

10. Who take care the retarded person? (If fully dependant on others) -----

Why care is needed? -----

11. What sort of care/nursing is needed? -----

12. Prenatal duration? -----

13. Standard diet of the pregnant mothers    VG/ G/ A/ P/ VP

14. Serious disease/ illness during pregnancy period?    Yes/ No

15. Anxiety during pregnancy period?    Yes/ No

16. Regular physical check-up during pregnancy period?    Yes/ No

17. Duration of labour pain?

18. Type of birth?

Spontaneous/ normal/ caesarean/ instrumental/normal after prolonged labour.

### Education of the Mentally Retarded Person

1. Whether he was admitted to a primary school? Yes / No
2. How many days did he go to school? -----
3. Was there any problem during school admission? Yes / No
4. What were the problems? -----
5. Does he go to school at present? Yes / No
6. Why does not he go to school?
  - a) Cannot perform the school tasks    b) Other children disturb him
  - c) Teachers asked him not to go        d) Other reasons -----
7. Did you try to give him/her education at home? Yes / No  
How you tried? -----
8. Have you taken advice of a special teacher or counselor? Yes / No  
What advice they have given to you? -----
9. Is there any special education for the mentally retarded persons  
in your locality? Yes / No  
What facilities are there? -----
10. How the child go to school?
  - a) Walk by himself                            b) Someone accompany him to school
  - c) With others by van                        d) Carried by someone
  - e) In some other way -----
11. Do you think the special education is necessary for the  
Mentally Retarded persons? Yes/No  
Why ? -----
12. What kind of education is necessary? -----  
What kind of curriculum is necessary? -----
13. Who will run this type of education?
  - a) Government    b) Union Parisad    c) NGOs
  - d) The family of the retarded persons    e) Somebody else (Who?) -----
14. Which is the best place for special education?
  - a) Integrated inside ordinary schools    b) Separate school    c) In the house  
of the retarded person
  - d) Somewhere else (Describe) -----



### Employment of the Mentally Retarded Person

1. Can your child do anything? Yes / No  
 What can he do? -----
2. Have you taken any step from your family to make your retarded person employed? Yes/No  
 What steps have you taken ? -----
3. Does your handicapped child possesses any scope of employment in your locality? Yes / No  
 What scope does he have? -----
4. Is he employed any where at present? Yes / No  
 Where? -----
5. Why not employed?  
 a) Unable to do anything    b) No scope to work    c) No body appoints him in work  
 d) He is not in the age of doing anything    e) Other reasons: -----
6. What steps are necessary to give him employment opportunity? -----
7. Who will create such scope? -----  
 How will they do it? -----
8. Which technical training is suitable for the handicapped person?  
 a) Farming                      b) Carpentry      c) Household works      d) Poultry  
 e) Family business      f) Dairy              g) Handicrafts      h) Small shop  
 attached to the house  
 i) Other (Please specify) -----
9. Do you think retarded person should participate in jobs according to their skill? Yes / No  
 Why? -----
10. Is your handicapped child receiving any government grant? Yes / No  
 If any, Please describe: -----

### Housing of the Mentally Retarded Person

1. Where do you keep your Mentally Retarded child?
  - a) Together with others in family
  - b) Separately (where?) -----
2. Does the handicapped child live in an independent bed room? Yes / No  
 Where the room is located? -----
  - a) In the same house with all others
  - b) In the room separately made for him
3. The type of house where the retarded person lives?
  - a) RCC roof
  - b) CI sheet roof
  - c) Mud-built house tin-shed roof
  - d) Grass roof
  - e) Hut
 Where does he/she sleep?
  - a) On the floor
  - b) On the bed
4. Who cleans his room? a) He / She himself / herself b) Someone else  
 (Mother/Employee)
5. Does he sleep out of the house at night for accommodation problem at home?
  - a) Yes (Where?) -----
  - b) No
6. How many dresses the retarded children have? -----  
 Whether the dresses are of the same standard like other family members?  
 Yes / No  
 Is he/she given the same standard food like the other members of the family?  
 Yes / No
7. Which is the proper living place for the retarded person?
  - a) Own family
  - b) Group home
  - c) Some where else -----
8. Whether other members of the family like to live in the same house with him/her?
  - a) Yes
  - b) No (Why?) -----
9. Where will he / she live in your absence?
  - a) In the same place where he is living now
  - b) There are separate house arrangements
  - c) Somewhere else (Where?) -----
  - d) Don't know
10. What things are needed for better housing of the handicapped person?  
 How that can be achieved?.....

### Social Security of the Mentally Retarded Person

1. Do you let other people know the problems of your child?  
 a) Yes    b) No (Why?) -----
2. How do others behave with your child?  
 a) Behave normally    b) Annoy him / her    c) Humiliate him/her  
 d) Avoid him / her  
 e) Anything else : -----
3. Do you accompany him / her while visiting a relative's house or attending a ceremony?  
 a) Yes    b) No (Why not?) -----
4. Do you think that the retarded person should live with his / her family?  
 a) Yes    b) No (Why?) -----
5. Who should take the responsibilities of the handicapped persons?  
 a) The members of the family    b) Government    c) NGOs  
 d) Some other else (Describe) -----
6. Do you think that government should give some pension to the handicapped persons?  
Yes / No  
 Why? -----
7. What problems do you face because of your child's retardation?  
 (Describe) -----
8. Do you fasten or confine him / her with fear that he/she may be lost?    Yes / No  
 Does the retarded child get the opportunity of social mixing, sports and pastime like others?    a) Yes    b) No (Why?) -----
9. What problems does the handicapped child have for being female?  
 Are you worried that she is female? Why? -----
10. What opportunities should be created for their integration in the society? -----  
 -----

### General Question

1. Is your family joint or single?  
 a) Joint family    b) single family
  2. How many members are there in your family? -----  
 How many persons earn? -----  
 What is the total income of all members per year? -----
  3. Will you arrange marriage of your retarded child?  
 a) Yes (How? Why?) -----  
 b) No (Why?) -----
  4. What problems do you face in you family life for your child's retardation? -----
  5. Was there any problem of the mother during pregnancy or child-birth?  
 Yes / No  
 What problems? -----
  6. How old were you (husband and wife) at the time of the birth of the  
 handicapped child?  
 a) Husband -----years      b) Wife -----years
  7. Whether the parents are close relations? Yes / No  
 What kind of relationship? -----
  8. What is the main reasons do you think responsible for the retardation of your  
 child? -----
  9. What do you think about the future of the handicapped child ?
  10. Is there any other person like him/her in your family or close relatives?  
 Yes / No  
 Who? -----
- Researcher's Self Report about mentally retarded persons -----

**Percentage distribution of disabled persons by type of disability, broad age group and sex, 1991\***

(In percent)

Age group and sex	Percentage of total population	All disabilities	Type of disability				
			Blind	Deaf and dumb	Crippled	Mentally handicapped	Leprosy
Bangladesh total	0.47	100.0	17.4	20.8	44.0	15.3	2.5
0-4	0.25	100.0	16.7	19.4	48.8	14.7	0.4
5-14	0.47	100.0	15.9	24.8	44.1	12.6	2.6
15-29	0.63	100.0	14.5	24.0	39.4	18.9	3.3
30-49	0.14	100.0	13.2	16.2	37.0	29.4	4.2
50-64	0.53	100.0	27.4	15.0	41.5	15.4	0.7
65 and above	1.50	100.0	23.4	11.3	55.2	8.0	2.0
Male. total	0.41	100.0	15.6	22.0	43.0	16.4	3.0
0-4	0.28	100.0	15.2	20.5	49.6	14.6	0.0
5-14	0.47	100.0	16.4	25.4	42.6	12.5	2.9
15-29	0.72	100.0	15.2	23.3	40.1	18.0	3.4
30-49	0.11	100.0	13.4	9.2	37.1	34.0	6.2
50-64	0.11	100.0	14.7	5.9	52.9	23.5	2.9
65 and above	0.50	100.0	15.3	12.6	57.7	11.7	2.7
Female. total	0.53	100.0	18.9	19.8	44.7	14.4	2.2
0-4	0.21	100.0	18.7	17.8	47.7	15.0	0.9
5-14	0.47	100.0	15.2	24.1	45.7	12.6	2.3
15-29	0.55	100.0	13.5	24.9	38.4	19.9	3.2
30-49	0.17	100.0	13.0	21.0	37.0	26.0	2.9
50-64	1.01	100.0	29.0	16.2	40.0	14.3	0.4
65 and above	2.70	100.0	25.2	11.1	54.6	7.2	1.8

\* Provisional.

Source: Population Census [Sample Survey] 1991. BBS.

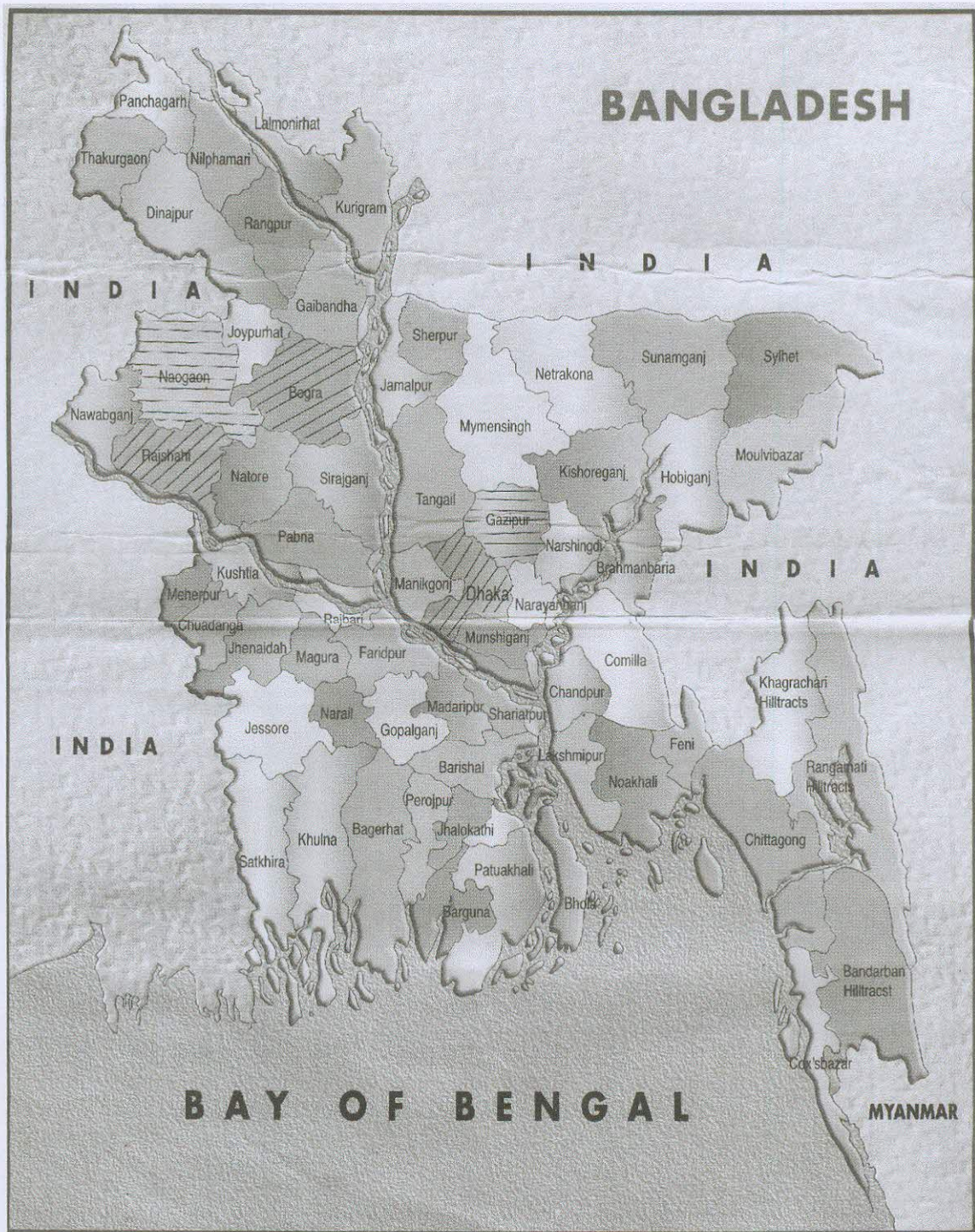
## Health Situation in the South-East Asia Region, 1998-2000 Bangladesh

Indicator	Latest available data	Year	Source
<b>Population and Vital Statistics</b>			
Total population (in millions)	129.2	2001	3
Crude death rate (per 1000 population)	3.7	2000	3
Total fertility rate (per woman)	2.5	2000	3
<b>Environment</b>			
Population with safe drinking water			
<b>Total</b>	97.3	1999-00	2
available in the home	Urban	1999-00	2
or within reasonable access (%)	Rural	1999-00	2
<b>Health Resources</b>			
<i>Facilities</i>			
Number of hospital beds	43,443	2001	4
<i>Human resources</i>			
Number of registered physicians	32,498	2001	4
Population per physician	3,977	2001	4
Number of registered nurses	18,135	2001	4
Number of midwives	15,794	2001	4
Physician to Nurse ratio	2 to 1	2001	4
<b>Health Services</b>			
Deliveries attended by trained personnel (%) 7.1% by doctors, 5.0% by nurse/ midwives, 9.7% by trained TBA	21.8	1994-99	4
<b>Health Status</b>			
Life expectancy at birth (years):			
Total	61.8	2000	3
Male	60.7	1998	
Female	60.5	1998	
Infant mortality rate(per 1000 live births)	51.0	2000	3
Under-five mortality rate (per 1000 live births)	82.4	1998	1
Maternal mortality ratio (per 1000 live births)	2.3	2000	3

**Sources:**

1. Bangladesh, Ministry of Health and Family Welfare, Bangladesh Health Bulletin 1998-99 (draft), Dhaka, August 2001
2. Bangladesh, Demographic and Health Survey 1999-2000, Dhaka, May 2001
3. Bangladesh, Bangladesh Bureau of Statistics, 2000. Statistical Yearbook of Bangladesh (21<sup>st</sup> edition) Dhaka.
4. Bangladesh, Unified Management Information System (UMIS), DGHS, Dhaka.

[http://w3.whosea.org/health\\_situt\\_98-00/annex1ban.htm](http://w3.whosea.org/health_situt_98-00/annex1ban.htm)



Map: Showing study areas

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