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# Medical and Psychosocial Care of The Mentally Retarded Persons in Bangladesh

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University of Rajshahi

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**MEDICAL AND PSYCHOSOCIAL  
CARE OF THE MENTALLY  
RETARDED PERSONS IN  
BANGLADESH**



**Thesis submitted for partial fulfillment of the Degree of  
Doctor of Philosophy**

**in the  
Institute of Bangladesh Studies  
University of Rajshahi**

**by  
Muhammad Shamsul Alam**

**December 2014**

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**by  
Muhammad Shamsul Alam**

Under the supervision of

**Anwarul Hasan Sufi**  
Professor of Psychology  
University of Rajshahi

**December 2014**

## **Certificate**

Certified that the thesis entitled '**MEDICAL AND PSYCHOSOCIAL CARE OF THE MENTALLY RETARDED PERSONS IN BANGLADESH**' has been completed by Muhammad Shamsul Alam of the Institute of Bangladesh Studies, Rajshahi University for the award of Ph.D. Degree. The work has been done under my supervision.

I now recommend for the examination of the thesis.

Anwarul Hasan Sufi  
Research Supervisor

## **Declaration**

This thesis entitled ‘**MEDICAL AND PSYCHOSOCIAL CARE OF THE MENTALLY RETARDED PERSONS IN BANGLADESH**’ contains no material which has been accepted for the award of any other degree or diploma in any university and contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Muhammad Shamsul Alam

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## **Abstract**

Intellectual disability or mental retardation is a worldwide problem. The people suffering from mental retardation, themselves, their families and the society face enormous problems for their condition. Care for mental retardation has extensive aspects and needs elaborate arrangement. Throughout the world as well as in Bangladesh the problem is not duly addressed. So the sufferings for this problem are too much in our families and societies. The objective of the study was to assess the state of medical and psychosocial care for these people in Bangladesh and how to improve it.

There is no national survey related to the prevalence of Intellectually Disabled people in Bangladesh.

The study was done by taking case studies of 90 mentally retarded persons of different age, sex, education, economic and other perspectives. Respondents were mainly the parents of the mentally retarded persons. 30 cases were studied in Dhaka City, 20 cases in Rajshahi City and 40 cases were studied in different villages around Rajshahi University. The study period was from April 2012 to June 2014. Purposive sampling was done. The data was collected by semi-structured questionnaire along with socio-demographic information. It was in Bangla for the convenience of the respondents. All collected data were checked, rechecked for omission, inconsistencies and improbabilities. Data analysis was performed by Statistical Package for Social Science (SPSS). Ethical issues were considered duly in collecting data.

The results showed that majority of the respondents (55.5 %) were not aware about the genetic causes of mental retardation. Possible genetic causes for mental retardation were found as, hereditary diseases in the family's (38.89%), history of previous abortion and neonatal death (10%), maternal age 35 and above (4.44%) and consanguinity among the parents (11.11%). Measures taken to prevent hereditary causes of mental retardation was found in 20% cases. Care for pregnancy and labour was taken as vaccination in 84.4%, regular checkup in 77.8%; nutritious food, vitamins, folic acid was taken by 62.2% cases. Measures for safe development of fetus were taken in 36.4% cases.

During infancy and childhood vaccination was taken in 91.1% cases. Screening test for mental retardation was done only in 18.89% cases. Medical care for mentally retarded persons were taken by specialist doctors in 25.6% cases. In 62.2% cases it

was found that they were treated by multiple system of treatment. In 58.9% cases there were multiple psychological / emotional problems with the related society. Integrated education was proposed by 48.9% respondents, sheltered especial job was suggested by 66.7% respondents. 37.8% respondents thought that community should arrange home for the mentally retarded persons. 74.4% respondents think that mentally retarded persons should live within the society, preferably in own families with special care. 65.6% respondents think for integrated arrangement of different types of recreation. Majority of the services for the mentally retarded persons came from families, relatives and neighbors (45.6%). The respondents evaluated the services as poor in majority of the cases (56.7%).

It was found that the awareness about genetic causes of mental retardation is yet inadequate, which is due to less dissemination of knowledge. Urban, rich and highly educated people know more about hereditary diseases and so they noticed it more. Neonatal death or abortion is less as people are more conscious now a day than previous time. Consanguinity is also less due to awareness. Most of the respondents took no measure for prevention of hereditary diseases, which may be due to negligence or less consciousness in this regard. Maternal care now has improved in Bangladesh due to Government and other initiatives. Vaccination during pregnancy and care during delivery are better and more scientific now a days. Immunization is a successful programme in Bangladesh and it is praised by all. It is hoped that 100% immunization will be possible in Bangladesh very soon. Screening tests for mental retardation is just beginning in Bangladesh. It is hoped to be extended in near future. Most of the respondents took multiple system of medical care for their mentally retarded children, which indicate their indecision mixed with emotion about the care as well as scientific attitude and specialized care for these people. Most of the services come from families, relatives and neighbours, which indicates that Government and social organizations are not duly performing their roles in this regard. Finally the care provided to the mentally retarded persons was evaluated as poor by most of the respondents. It indicates that though the services are gradually improving it is not to the scale as per need and expectation.

It can be concluded that in many respect the situation of care for the mentally retarded persons is improving, while in other areas it is neglected. The preventive measures, screening test should be developed and extended. It is recommended to set up a separate special discipline in medical system of the country for mental retardation, which will deal with the prevention, treatment, care and research in the related fields.



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# **Chapter I**

## **Introduction**

### **Preamble**

The researcher observed the mentally retarded persons from his early life in his neighborhood and in different social situations. His parents, teachers and all other respectable persons of the society to whom he came in contact, they all taught him to do something for these handicapped persons.

In his primary school life, as he remembers, he had some classmates who were mentally retarded, but not properly identified or treated for their problems at that time. Truly speaking at that time there was no awareness or any knowledge among the people, social leaders and experts in the society in this branch of science. Later, when the researcher became medical graduate he had new outlook about the problems. He became more concerned and acquired some knowledge about its medical background and its psychosocial perspectives. Thereafter when his post graduation in psychiatry was completed he tried to know more in depth and specific knowledge related to this condition. Then he decided to do a research in this field.

To the best of the knowledge of the researcher, until 1977 practically nothing was done for the mentally retarded Children in Bangladesh. It is well recognized that Professor Dr Sultana S Zaman of Dhaka University Psychology Department is the pioneer to do something for these Children. The concerned professionals gradually became serious when Dr Sultana Zaman started a Special Education Class for the mentally retarded children inside Dhaka's wills Little Flower School.

Mental retardation is a worldwide problem and it is as ancient as the history of mankind. In the ancient time mental illness and mental retardation were considered as the same entity. Paracelsus (1493-1541) first distinguished between mental illness and mental retardation (Scheerenberger, 1983). The Concept of mental retardation includes deficit in cognitive abilities as well as in behavior required for social and personal sufficiency, known as adaptive functioning (Sadock & Sadock, 2007; Horwitz et al., 2000).

People with mental retardation are unable to do for themselves and the society. History says that the society was not kind to these people. Once they were thought to be possessed by the devils or evil spirits. Many of

them were executed. They were forced to beg, humiliated, and their livelihood was too much tough (Griffin, McClidock, 2007).

In the 18<sup>th</sup> century science began to replace superstitions and inhuman ideas. Biology and other sciences were used to explain the condition. Instead of spiritual deficit, people with disabilities were then considered as having genetic deficit. They were then placed under the care of medical professionals, professional educators and social workers. It began to establish institutions for the care of the mentally retarded persons. Thus people's attitude towards the mentally retarded persons became humanistic gradually through a long period of time. But not until the seventeenth century the society began to organize institutions for them (Zaman, 1990).

In the eighteenth century many institutions were established for the care of the mentally retarded persons in Europe. In the nineteenth century due to enormous development of medical science, specially genetics, measurement of intelligence, greater access of the mentally retarded persons by the society, the previous view was changed. There were also many faults in the system of institutionalization. Nowadays it is thought that people with mental retardation should remain in the society as far it is possible. In developed countries the effort to deinstitutionalize and integrate the mentally retarded people in the society is more visible and it is also known as normalization (Gelder et al. 2006, Sadock and Sadock, 2007, Roos, MC Camn, 1977).

In Bangladesh formal services and cares for the mentally retarded people were absent during British, Pakistan and initial period of Bangladesh. In 1977 few parents of mentally retarded children, psychologists, psychiatrists, social workers under the leadership of Dr Sultana S Zaman established an organization named SCEMRC (Society for Care and Education of the Mentally Retarded Children), which was later renamed as (SWID, Bangladesh) Society for Welfare of the Intellectually Disabled, Bangladesh (Miles, 1996; Mamun, 2011). Some other organizations e.g. Bangladesh Protibondhi Foundation, Rehabilitation Institute and Hospital for the Disable (RIHD), Gram Bikash Shohaok Shangstha (GBSS) and SIVUS group were also founded in course of time. Many other organizations, psychologists, psychiatrists, social workers are also providing services to them individually. Ministry of Social Welfare's one of the important services is to uplift the life of the mentally retarded persons. Many other ministries and departments of the government are giving part of their services to them. Among the services; education,

rehabilitation, medical care, advocacy program, guardianship and life long care, public awareness, training and employment are important. The Bangladesh government has enacted “Protibondhi Kallyan Ayn-2001” (Disability Welfare Act-2001) in the parliament in 2001. Currently the law is being reviewed for amendment to make it in accordance with the UN convention on the rights of persons with disabilities (Ferdous, 2009, A Bi monthly web-zine, 2001).

There are approximately 4.6 million people with mental retardation in Bangladesh according to World Health Organization (Ferdous, 2009). Among them only a few thousands are getting formal services to some extent (Mamun, 2011). The services for the mentally retarded people are too much elementary as per its quality and quantity. In this perspective it demands greater effort to change the situation.

## **Mental Retardation**

The terminology, concept and definition of mental retardation has changed from time to time and yet it is not the same everywhere. It was mentioned earlier that during ancient time mental illness and mental retardation was considered as the same entity. Pacelsus (1493-1541) first distinguished between mental illness and mental retardation. But many others continued to think as before. Felix Platter (1536-1614) first described 'mental alienation' including mental retardation and mental illness. This notion persisted until the early 20<sup>th</sup> century and with those interested in the practice of psychiatry being known as 'alienists' (Scheerenberger, 1983). Felix described a multilevel description of mental retardation, where he stated that some people were too much simple or foolish, slow in their movements, less attentive, docile and less able to learn. He stated other category who were less foolish, correctly performing many tasks, possessing certain skills, yet having dullness. He then stated another group, who were dull from before birth, having deformed heads or swollen tongue, humorous throat or deformed in general appearance. Thus he described different levels that may said to be in some way similar with the modern days classification of mental retardation (Scheerenberger, 1983). In 1845, Esquirol while mentioned mental retardation wrote "Idiocy is not a disease, but a condition in which the intellectual faculties are never manifested, or have never been developed sufficiently to enable the idiot to acquire such an amount of knowledge as persons of his own age and placed in similar circumstances with himself are capable of receiving" (Gelder et al., 2006).

In the nineteenth and early twentieth centuries the word idiot, imbecile, mentally deficient were used for intellectually impaired people of early age. To avoid the stigma it was then termed as 'mental sub normality' and 'mental retardation'. The term 'mental handicap' is also in use. Now the term 'learning disability' is preferred in the United Kingdom. But still in ICD-10 and DSM-IV the term 'mental retardation' is used (Gelder et al., 2006).

## **Definition**

According to DSM 5, introduced in May 1914, the term Mental Retardation was changed to Intellectual Disability.

Various authorities defined mental retardation differently. According to DSM-1V (Diagnostic and Statistical Manual 1V) the definition of mental retardation is as followed, "a significantly sub-average general intellectual functioning, that is accompanied by significant limitation in adaptive functioning in at least two of the following skill areas: communication, self care, home living, social/interpersonal skills used for community resources, self direction, functional academic skills, work, leisure, health and safety and having an onset before the age of 18" (Gelder et al., 2006).

According to the World Health Organization, mental retardation is "incomplete or insufficient general development of mental capacities" (Gross HJ, 1977). American Association on Mental Retardation (1992) defined mental retardation as the onset of significant limitation in both general intellectual and adaptive functioning during the developmental period (18 years and under) (AAMR, 2000). Considerable controversy exists regarding the definition, but it was intended to broaden the definition as more individuals can get the services (Horwitz et al., 2000).

## **Levels of Mental Retardation**

In both ICD-10 (International Classification of Diseases) and DSM-IV (Diagnostic and Statistical Manual-1V) mental retardation is classified as, mild (IQ 50-70), moderate (IQ 35-49), severe (IQ 20-34), profound (IQ below 20) (Gelder et al., 2006). Mild mental retardation is found in 85 percent of persons with mental retardation and not detected until after first or second grade, when academic demand becomes high. Then they are slow in achieving academic skills. The cause of mental retardation is often remain unknown. Many mild mentally retarded people can live independently with due support and family environment (Sadock & Sadock, 2007).

Moderate mental retardation is found in 10 percent among the persons with mental retardation. Most of them can acquire knowledge and can communicate in early childhood. But they are weak in academic skill and can't go above second to third grade level. In adolescence they face difficulty in socialization and require various social and vocational supports. In adulthood they can do semiskilled work under supervision (Sadock & Sadock, 2007).

Severe mental retardation is found in 4 percent of the persons with mental retardation. In childhood they develop communication skill and learn to count & recognize words. In adulthood they require supervised living situation and work-related tasks (Sadock & Sadock, 2007).

Profound mental retardation is found in 2 to 3 percent of persons with mental retardation and they have definite causes of their condition. They may be taught some self-care skills and to communicate by appropriate training (Sadock & Sadock, 2007). In DSM-IV TR there is a type, where severity is unspecified, for those who are strongly suspected to have mental retardation but can't be tested by standardized intelligence tests or uncooperative to be tested. They are judged clinically, IQ can't consider numerically (Sadock & Sadock, 2007).

## **Epidemiology**

The prevalence of mental retardation depends on many factors e.g. definition of mental retardation, the population studied and advances in medical technology.

Definition of mental retardation is an integral part for determining prevalence as it is related with the inclusion or exclusion of a person whether he should be considered mentally retarded or not. Prevalence may vary according to the category of study. Population based study and service-use based study give different results. Advances in medical technology have a great impact on prevalence of mental retardation. Now a days due to improved medical treatment the longevity of life of the mentally retarded persons is increasing. So the prevalence rate is higher than the previous time.

On the other hand due to adopting more measures for preventing mental retardation e.g. maternal and neonatal care, vaccination, genetic screening and other measures the prevalence is also decreasing (Horwitz et al., 2000). 2.0-7.5 million Americans of all ages may have mental retardation and 1 in 10 families are directly affected by mental retardation. Many reports stated the population prevalence of mental retardation in United States is as high as 3.0%.

It is varied in different states of USA ranging from 0.3% to 3.1%. In other developed countries it is lower e.g. in Sweden it is between 0.3% to 0.7%. But it may be due to the use of higher IQ cut off (<80) in Swedish studies (Horwitz et al., 2000). In England, moderate and severe mental retardation, arrested development or severe abnormality among children and adults are found to range from 0.3% to 0.5%. A



study using a surveillance registry in British Columbia the overall mental retardation prevalence rate was found to be similar (0.4%), with 0.1% mild, 0.1% moderate, 0.05% severe, 0.04% profound and 0.01% unspecified mental retardation. In Ireland, using an IQ cutoff 50 (severe MR), the rate of mental retardation among adults of 20-29 was found to range from 0.4% to 0.6% (Horwitz et al., 2000). In less developed countries, percentages of mental retardation are generally higher.

From Bangladesh Islam et al. (1993) reported it to be 1.6%-3.0%. But recent studies showed it to be lower. In China it is found to be ranged between 0.4% to 0.7%. A study in Cape Town, South Africa, using administrative data it was found to be 0.3%. In India a study using an IQ <80, it was found to be 0.4% in the general population and 1.0% among the children. In Bangladesh it was found in a population based study in 1993 the rate of 0.6% for severe mental retardation, and 1.4% for mild mental retardation (Horwitz et al., 2000).

## **Co morbidity**

### **Physical disorders found among the mentally retarded persons**

Physical disorders are common among the mentally retarded people. But it is tough to diagnose the illness due to their low IQ and less expressive ability. Among the diseases which are more in these population are ear infection, dental caries and skin diseases (Gelder et al., 2006; Horwitz et al., 2000, Jansen et al., 2004). Epilepsy is found in 14-24 percent of people with mental retardation compared to 5% in the general population. It is more in relation to severity of mental retardation. Mentally retarded people suffer from certain diseases which are related to the causes of their condition, which may be heart disease, cerebral palsy, vision and hearing impairment speech and language problem, and behavioral problems (Gelder et al., 2006).

In Bangladesh the mentally retarded persons are neglected. Many families try to hide their mentally retarded family members. There is no national wide survey in this regard. The researcher studied some partial, fragmented picture from other researchers. He also consulted with other doctors. From their views from his own observation he found that many of the mentally retarded persons in Bangladesh also suffer from other sorts of disabilities and diseases. They suffer from deficit in vision, hearing, locomotor abilities and less functioning of all organs. But they visit least to the doctors. They also suffer from fever, diarrhea, respiratory tract infection, epilepsy and other neurological disorders, heart diseases, dental and skin problems. But their guardians and society is not duly aware and not taking care for them.

## **Psychiatric disorders among the mentally retarded persons**

Psychiatric disorders are reported to be higher among the mentally retarded people than the general population. The more common mental diseases are mood disorders, schizophrenia, attention-deficit hyperactivity disorders (ADHD), and conduct disorders (Gelder et al., 2006; Sadock & Sadock, 2007). 2 to 3 percent of the mentally retarded persons are found to have schizophrenia compared to 1 percent in the general population. 50 percent of them have mood disorders. Highly prevalent psychiatric symptoms are hyperactivity, short attention span, and self injurious behavior. Their self-image is negative, self-esteem is low, frustration tolerance is poor, and can't solve the problems. They suffer from various psychopathologies. (Gelder et al., 2006; Sadock & Sadock, 2007).

In Bangladesh, in a nationwide survey, 16.05% of the population found to have mental diseases. In comparison to that among the mentally retarded persons it was found 47.9% as reported by MZR Khan (Unpublished dissertation, 2010). The researcher found in his medical practice that most of the mentally retarded persons had behavioural problems; many of them suffer from schizophrenia, mood disorder. They suffer from inferiority complex, feel humiliated, helpless, and hopeless and neglected by others.

## **Etiology**

Though our scientific knowledge has increased, still the etiology of mental retardation is unknown for about 50 percent of cases. The causes which are detected can be classified as (1) genetic conditions (2) problems during pregnancy (3) problems at birth (4) problems after birth (5) poverty and cultural deprivations (The Arc, 2005). Most frequent genetic causes are Down's syndrome, Fragile X syndrome, Patau syndrome, Edwards syndrome, cri du chat syndrome and many others. These are chromosome related genetic disorders. Some others are metabolism related genetic disorders e.g., phenylketonuria, Tay-Sachs disease, citrullinuria, Lesh-Nyhan syndrome etc. There are many rare genetic diseases which cause mental retardation (The Arc, 2005). Problems during pregnancy may be malnutrition, certain environmental toxins, rubella and syphilis. Use of alcohol by pregnant mother can cause mental retardation. Problem at birth may be prematurity, low birth weight, difficulties in birth e.g. Oxygen deprivation, birth injury may cause mental retardation (The Arc, 2005). After birth, childhood diseases such as whooping cough, chicken pox, measles, and Hib leading to meningitis and encephalitis can damage brain. Injury such as blow on head and near drowning, these can cause mental retardation. Lead, mercury and other environmental toxins can cause in repairable damage to the brain and nervous system (The Arc, 2005). Poverty and cultural deprivation may cause malnutrition, childhood diseases, exposure to environmental health hazards and to get inadequate health care. They lack of cultural and educational resources, which cause under stimulation thereby irreversible damage leading to mental retardation (The Arc, 2005).

## **Assessment**

The stages of assessment are history taking, physical examination, examination of the mental state, developmental testing functional behavioral assessment, and analysis of the interaction between the disabled person and the family, social support system and other aspects of adjustment (Gelder et al., 2006). In Bangladesh the first assessment tools were introduced by Dr Sultana Zamans team. The questionnaire developed by Dr Shirin Zaman Munir was used SCMRB Dhaka and Rajshahi during 1977-1984. Later considering the need several behaviour check-list were developed by the psychologists and psychiatrists.

### **History taking**

It includes family history, e.g. consanguinity, inherited disorders, abnormalities in pregnancy and delivery. Account of developmental milestones, behavioral problems should be taken. Associated medical condition such as congenital heart diseases, epilepsy and cerebral palsy should be noted (Gelder et al., 2006). In Bangladesh, history taking is widely used by all the service providers, investigators and researchers. Individual investigators developed many questionnaires to facilitate their own interest areas.

### **Physical examination**

Recording of head circumference, physical other signs suggesting any specific Syndrome should be obtained. Neurological examination including hearing and vision test is important. Neuro imaging may supplement the physical examination. Now a days many areas of physical examination of the mentally retarded persons are included. Child Development Center of Dhaka Shishu Hospital developed Check-List of physical examination.

### **Psychiatric examination**

The verbal abilities of the mentally retarded persons, including receptive and expressive language, by observing the communication between the caretaker and the patient and taking the history. Control over mobility patterns, evidence of distractibility and distortion in perception and memory should be evaluated. The use of speech, reality testing, and the ability to generalize from experience should be noted. The nature and maturity of the patient's defenses, particularly exaggerated or self-defeating uses of avoidance, repression, denial, introjections and isolation should be observed. Frustration, tolerance, and impulse control especially over motor, aggression, and sexual drive should be assessed. Self-image and its role in the development of self-confidence, as well as an assessment of tenacity, persistence, curiosity, and willingness to explore the unknown are important. Psychiatric examination of related person will reveal how the person coped the developmental stages (Gelder et al., 2006; Sadock & Sadock, 2007). In Bangladesh, psychiatric examinations are relatively low during first time assessment of the cases. But the first assessors are now a days frequently referring cases to the psychiatrists for investigations.

## **Developmental assessment**

It is based on clinical examination and standardized methods of measuring Intelligence, language, motor performance and social skills. IQ measurement is the best general index of intellectual development. But in too young children and severe mentally retarded persons it is not reliable. Tests used in IQ measurement are Wechsler Adult Intelligence Scale (WAIS) and other IQ measures which is applied in particular skills. An abbreviated version of WAIS the Wechsler Abbreviated Scale of Intelligence (WASI) is also available. Another useful, quick method is Picture Vocabulary Test or Raven's Progressive Matrices. The other commonly used instruments are Vineland Social Maturity Scale, The British Ability Scales, and Differential Ability Scales, The Adaptive Behavior Scales, The Portage Guide to Early Education, Autism Behavior Check List, The Disability Assessment Scale, British (Peabody) Picture Vocabulary Test and Rainelle Scales of Language Development. Some of these tests give general and other tests give specific assessment of developmental domains. All of the tests have remarkable reliability and validity.

## **Laboratory examination**

These tests are chromosomal analysis, urine and blood testing for metabolic disorders and neuro-imaging which will explore the causes of mental retardation. Chromosomal abnormalities are the single most common cause of mental retardation. Amniocentesis and Chorionic Villi Sampling(CVS) are screening Technique for detecting chromosomal abnormalities. Lesh-Nyhan syndrome, galactosemia, phenyl ketonuria, Hurler's syndrome and Hunter's syndrome and such other disorders which include mental retardation can be detected by assaying appropriate enzyme or organic amino acids in blood or urine (Gelder et al., 2006., Sadock & Sadock, 2007).

There are highly qualified scientists and most modern instruments in many medical colleges as well as in the Public Universities. But there are scarcities of skilled technicians to prepare the specimens. To conduct an Amniocentesis, experts are there, but skilled technicians to draw the amniotic fluid from the pregnant mother's would are rarely found.

Secondary, the interpretation of different laboratory tests sometimes become controversial when the same sample are sent to two different scientists in Bangladesh. Whereas, in Sweden, Amniocentesis is

compulsory for all who conceive after age 35 years. In 1947 the prevalence of mentally retarded children was 3% in Sweden. Only using Amniocentesis in 1987 the prevalence reduced to 0.47% of the Swedish population.

For reliable and valid laboratory tests we need to give emphasis to increase skilled technicians, too.

## **Care of the Mentally Retarded Persons**

The main elements of services for the mentally retarded persons are (1) prevention and early detection of mental retardation (2) regular assessment of their abilities and disabilities (3) advice, support and practical measures to the families (4) education training, occupation for each of them (5) housing and social support (6) medical, nursing and other services, (7) psychiatric and psychological services (Gelder et al., 2006; Girimaj et al., 2001). Primary prevention may be genetic counseling, early detection of fetal abnormalities during pregnancy and safe delivery. Secondary prevention is to limit the disability by physical or psychological means. This may be done by education and early attempt to reduce behavioral problems (Gelder et al., 2006; Girimaj et al., 2001). Assessment should began from the early stage. Family doctors and teacher should learn to detect the condition. Then full assessment may be done in special centre when required. Once mental retardation is diagnosed, regular review is necessary by an interdisciplinary child health team in coordination with teachers and social workers (Gelder et al., 2006; Girimaj et al., 2001).

Families require help from the first diagnosis. They should be given full explanation and all its implications. Then support is to be continued. When school life is started, parents should be informed about the progress, involved in planning and care. They should be provided practical helps such as day care, baby-sitting, family holidays, and continuing psychological support (Gelder et al., 2006).

Their education should be given in the mainstream school as far as it is possible. Remedial classes may be added for them if required. An advantage of integration in the ordinary school is that other pupils will accept them as a social norm. When mentally retarded children leave the school, they should be reassessed and provide vocational guidance. Most of the mentally retarded persons can do normal jobs and sheltered employment. Severely disabled may be trained in day centre and provide relevant activities (Gelder et al., 2006). The mentally retarded children should remain with their parents and they should be

helped by all others to help them in this purpose. Their housing should be supported by the society and all other authorities (Gelder et al., 2006). Mentally retarded people should have easy access to all medical facilities as well as extra support as per their needs. Psychiatric care should be given them as they are more vulnerable to mental problems (Gelder et al., 2006).

### **Medical Care**

Medical care or health care is the professional care regarding diagnosis, illness, injury and other physical and mental problems of humans. It is provided by medical doctors, medical assistants, nurses, pharmacists, homeopaths, ayurveds and other traditional healers and many other care providers. It has hierarchy of levels, such as primary care, secondary care tertiary and quaternary care. Health care has many related sectors such as health systems, health care industries, health care research, health care financing, health care management and administration, health information technology (HIT) (World Health Organization. Health System. Geneva, 2009).

A social and economic condition and health policy determines the access of the people to medical care. There are differences in the quality of medical care across countries, groups and individuals. According to the World Health Organization (WHO) (2009), well functioning health care system should have good financing, competent work force and all other facilities and logistics to deliver due medical care. Health care is the important determinant of health and wellbeing of people of the world.

### **Primary care**

Primary care is served in the local community by primary care physicians such as general practitioners or family physician or medical assistants or nurse practitioners or other relevant persons as per custom of the country or community.

It includes all ages of patients, of all socioeconomic and geographic origins, seeking widest scope of health care, whether physical, mental or social health issues. Common illnesses are day to day health problems and diseases e.g. fever, diarrhea, skin diseases, respiratory problems, hypertension, diabetes, asthma, depression, anxiety, back pain, arthritis or thyroid dysfunction. It also includes basic maternal and child health care, family planning and vaccination. The World Health Organization considers primary health care as the integral and basic component of health care strategy. The international conference at

Alma Ata in 1978 set a goal of ‘Health for all by the year 2000 AD’ for all the countries of the world to attain the goal of Primary Health Care (PHC). As a signatory, Bangladesh also has taken strategy for such health services to its citizens (Ara, 2008). In Bangladesh Government is the Primary actor in the health sector. With it now private initiatives are also running. Beside these NGOs are also providing health services. Less than 40% of the populations get modern primary health care services beyond immunization and family planning. Only 25% pregnant women receive antenatal care and only 14% births are attended by trained personnel (Ara, 2008).

### **Secondary care**

It is the medical care provided by the medical specialists, who usually don’t have first contact with the patients, rather referred by the primary care physicians. These persons may be cardiologists, urologists, dermatologists, nephrologists, psychiatrists and so many others. Sometimes it means hospital care. In many countries secondary care is not available without prior referral from general physician or another physician, such as in United Kingdom or Canada. But in Bangladesh and many other countries there is no well established referral system. In Bangladesh a person’s can go to the specialist physician directly without referral from general practitioner or other physicians of special discipline.

### **Tertiary care**

It is specialized consultation medical care, inpatient services referred by primary or secondary care physician. In such care advanced medical investigation and treatment by well trained personnel and facilities are available (Johns Hopkins Medicine, 2011). These services may be required in cases of cancer, neurosurgery, cardiac surgery, plastic surgery, severe burn, advanced neonatal services, and in many high tech medical and surgical intervention (Emory University, 2011).

### **Quaternary care**

It is the extension of tertiary care and is highly specialized. Experienced medical, diagnostic and surgical methods are considered in quaternary care. These services are found in a limited centre only (Emory University, 2011; Alberta Rural Physician Action Plan, 2011).



There are many related sectors of medical care. *Health system* means organization of people, institution, and resources in order to provide health care as per need of the people. *Health care industry* provides health care services and products. It includes hospital activities, medical and dental practice activities, and 'other human health activities'. *Health care research* is the fundamental of developing medical science which results in improvement of overall medical care such as eradication of illness, better diagnosis and efficient treatment. These researches may be biomedical or pharmaceutical forming base of evidence-based medicine and evidence-based practice in medical care. *Financing in health care* is an important sector. The funding methods are taxation, health insurance, out of pocket payment, and donation. *Management and administration of health care* rules the practice of the health professionals and operation of health care institutions. It is vital to ensure the quality of medical care. Health information technology (HIT) is the information processing and its application by computer hardware and software that store, retrieve, share and use health care information, data and knowledge. It is important for communication and decision making.

Above the ideal state of medical care is described. But most of the people in Bangladesh and throughout the world are deprived of modern medical care. Modern medical facilities are not extended to the grass root level. Most of the people are getting care from the quack / village practitioners and faith healers. Though the situation is improving day by day but yet it is not to its expected level.

## **Medical care in Bangladesh**

Health care services in Bangladesh are provided by public, private (for profit), non government organization and traditional sectors. The public health care system is under the control and organization of the Ministry of Health and Family Welfare. It is highly centralized. The hierarchy of health care delivery system is as follows:

- (1) National
- (2) District
- (3) Thana
- (4) Union
- (5) Community

Among the above, first four stages are under the Ministry of Health and Family Welfare and the fifth one is served by the private health care providers (Ferdous Ara, 2008).

### **Medical care for the mentally retarded persons**

There is some special as well as the general aspect of the medical care for the mentally retarded persons. Mental retardation is incurable till now. So the main medical approach is to prevent the condition. But after establishing the diagnosis it requires general and special cares as per their needs. Among the preventive measures maternal care, prenatal diagnosis and screening, neonatal intensive care, genetic counseling etc are important. Thereafter it requires health promotion, specific promotion, specific treatment, early diagnosis and limitation of disability (Girimaj, 2001). These people's medical problems are in many cases different from others as it is related with their conditions, at the same time they require services as such the other people (Prater, Zylstra;2006).

### **Psychosocial Care**

Psychosocial care is aimed to the well being of an individual, who is the member of the society. This well being is determined by human capacity, social ecology and culture & values. These factors make a person to cope with the challenges of life-circumstances, complex emergency events and resulting conditions.

Human capacity is the physical and mental health, skills and knowledge of an individual and the community which enable their access to the resources in the environment. This capacity depends on overall health, age, gender, social/economic/educational concern and legal states.

Then social ecology is too much important. Social connection and support protects an individual, families and communities from conflicts and disasters. Various psychosocial programming with other humanitarian sectors promotes psychosocial well being. These programs may be educational, vocational, opportunities of play, strengthening peer groups, promoting family environment, community-driven reconstruction, building community linkage and economic development.

Various conditions, conflicts and disaster may disrupt the culture, values and sense of meaning which unite and give identity to a community. Human rights issues are related with culture and values. These values include religion and spirituality, traditional healing, conflict resolution, protection and safety. These should be revived and constructed for the psychosocial well being (Soudiere, 2000).

To achieve the above mentioned aims, the psychosocial care designed to help an individual on his strength and skills to deal with deficits, providing supports in order to live independently and as smooth as possible. It contains the following components: (a) basic living skills development (b) psychosocial skills training (c) therapeutic socialization (d) consumer empowerment (Guidelines by New Interagency Behavior Health, 2004).

In case of the mentally retarded persons these are to be modified accordingly. They require life long services. Their psychological problems, diseases, helplessness are to be given supports and solutions duly. Their social problems e.g. education, employment, family life, rehabilitation, participation in social activities and integration in the society are to be addressed properly.

We are to understand that adult mentally retarded persons are also the tax payers and voters in Bangladesh. But they are neglected in this country in many service providing areas. But mentally retarded persons also possess equal rights like all other persons to obtain services from government. The constitution of the country all protects their rights. They should be provided proper care and protection.

## Review of Literature

The researcher tried to review the relevant literature related to medical and psychosocial care of the mentally retarded persons in different books, journals and in the internet. He found that these are partial and do not meet the demand of the present days situation. Some of these are not relevant with the Bangladeshi perspective. However the researcher considered some articles relevant to this research and following are the summaries of those works.

Krauss and Class(2000) in their paper ‘The Road Ahead: Trends in Mental Retardation Services at the Beginning of the 21<sup>st</sup> Century’ described that the Governor’s Commission on Mental Retardation of Massachusetts examined the quality and effectiveness of the Commonwealth program of services designed to address the varieties of needs of people with mental retardation. They reviewed the situation regarding family directed supports and the challenge of self determination, community inclusion, housing opportunities, health care and many other aspects. For these they have done extreme literature review, telephone interviews with experts, public forum with the concerned persons. They found that national spending on family support grew from 1.6% of all MR/DD spending in 1992 to 2.3% of spending in 1996. Massachusetts is one of the top ten states in per capita spending for family support, with over 7.5% of the DMR budget allocated to this service. The authors saw that by maximizing choice of self determination the mentally retarded accomplished many of the goals e.g. to enjoy, such as tend a garden, help to maintain home, learn to cook and entertain friends. In respect of community inclusion the authors found the positive results of the concept of “Circles of support”. Regarding housing in 1988 was establishing the need to separate housing and support was clearly espoused. For health care it needed a system of organized health care from primary to highest level of specialty having home care, on-call and 24 hour nursing. The authors finally suggested facing the reality with more aspiration.

Jantova D.(n.d.) in his paper ‘The Care of the Mentally Retarded People in the Czech Republic: The Current Situation and Treatment’ discussed the important changes after the “velvet revolution” in 1989. The changes were mainly in social care, education, psychiatric treatment and in overall social situation. Then it was stable and secured environment, life long care, and easy access to systematic medical care. There was education even for the severe mentally

retarded which was absent in previous years. Psychiatric treatment was giving on outpatient or counseling basis. Only those were admitted whose behavior was aggressive. Regarding the overall situation it can be said that more people with mental retardation were living outside the institution, living at home, getting more help, their were varieties of caregivers and attending more in the schools. Finally the author concluded that the social and financial situation of people with mental retardation in the Czech Republic was improving, yet they need assistance of experienced specialists and researchers from other countries.

Nirje (1994) in his paper 'The Normalization Principle and its Human Management Implications' described what it meant by normalization and its effects. This principle referred to a cluster of ideas, methods, and experiences expressed in practical work for the mentally retarded people with underlying demands for standards, facilities and programs. These were based on age, degree of handicap, complicating physical and emotional disorders, social backgrounds, and educational and personal profiles. Some facets and implications were normal rhythm of day, routine of life, enjoying holidays, going on vacation for travel including abroad. Normalization includes opportunities to undergo normal developmental experience of life cycle, and to get choices, wishes, desires and respect for themselves. They should live in bisexual world, normal economic standards and physical facilities e.g. hospitals, schools, group homes, canteens. The normalization principle created a better social environment, it reduced social burden, rather contributed in social development. The author suggested that the persons allied with decision making bodies of society should be close to the mentally retarded people which will result appropriate and efficient programs.

Conroy and Spreat (2000) in their paper 'Comparison of Health Care Services in a Congregate Care Setting and in Supported Living Arrangements in Oklahoma' described that this study examined a variety of health care indices for persons with profound mental retardation who lived in a public institution in 1990 and in community based Supported Living Arrangements in 1995. The data suggested that approximately 10% of the sample had some difficulty in obtaining medical services in the community whereas 3% had such trouble in institution. But the overall greater access to medical personnel was increased but there were problem in obtaining specialty care or establishing initial medical care arrangements. In spite of these it was encouraging knowledgeable informants of the community were in

agreement with regard to the importance of need for medical care of the mentally retarded people. The author concluded that though some deficits remained still community placement was generally associated with positive life changes.

Blatt (1975) in his paper 'The Nine Pillars of Mental Retardation' discussed about the scientific concept, education, social consequences, human values, mainstreaming, expediency, and some other factors which are basically related with mental retardation. He said that the so called cultural familial or mild form of mental retardation is mostly preventable. They are educable to near normal extent. He then discussed about definition of mental retardation, where he said that it is not as precise as disease condition. To say about the consequences of mental retardation he gave opinion that defective persons result in defective society. He opined that the society should be helping towards these people, to be more flexible, receptive with acceptance of human variance. He said human values should be upgraded and sacrifice should be encouraged. About mainstreaming he stated that though it was a hopeful change but it should be done with thoughtfulness. He then concluded that competent leadership is required to upgrade the situation.

Ziring (1989) in his paper 'Health Care for Persons with Mental Retardation Living in the Community: Addressing the Gaps and Fragmentation in Services' commented that the health care services to the mentally retarded persons was not duly developed as it was developed other services to these people. In many cases it seemed that the mentally retarded people should require the previous arrangement of institutionalization. There were many gaps and the services were fragmented. The author proposed for a more rational and carefully thought policy for this extremely vulnerable and medically complex population. He suggested special centre and specially trained medical personnel for these people. It would act in collaboration with other sources of medical services. He concluded there should be a wide range of partnership e.g. state/local partnership, public/service delivery system partnership and so on. These arrangements could meet the health care needs of a patient with mental retardation in a competent and dignified manner.

Richardson (1989) in his paper 'Planning for Children and Adolescent who are Mentally Retarded and Have Substantial Medical Needs' said that mentally retarded children and adolescent had substantial medical needs due to their prematurity, birth trauma, or postnatal events,

multiple disabilities and many medical complications. So it requires thoughtful planning for their residential environment and other services. The medical needs of the mentally retarded were of various categories and services for them should be of various pattern. They may remain in home but when serious medical needs arise they require Hospitalization, and even it may require life supporting devices. The author classified the medical needs of the mentally retarded as (1) individuals with intensive medical needs, (2) individuals at risk for medical vulnerability, (3) individuals with significant needs. He suggested for (1) parent/ service delivery system partnership, (2) effective use of existing service resources, (3) minimization of staying in hospital, (4) flexibility and responsiveness in the service system, (5) planning for life span and ensuring adequate monitoring and evaluation.

Daniels (1989) in his paper 'Health Services in a Rural Setting: Sometimes D.D. in Mental Retardation Stands for Delights and Dilemmas' reported the experience of five years services in a rural setting. The author worked as the director of Sunment Developmental Disabilities Service Office (DDSO), Tupper Lake, which provided full range of services to people who were mentally retarded and developmentally disabled. The organization had 3500 clients at the time of this report and its services to them were residential care, alternative care or service in voluntary and state operated day treatment and day training, community residences, community ICFs, family care, personal care and various forms of supervised apartment living arrangements. Within five years it had moved from a custodial model of care to an active treatment service with individualized, integrated programming through an interdisciplinary team process. The service providers were physicians, dentists, nurses, PT, OT, speech and hearing therapists, psychologists, and dieticians along with a number of paraprofessionals. The author narrated about some delights and dilemmas. When they began their services in a usual way e.g. advertising and in such other means it gave no significant results. Then they adapted some innovative measures e.g. approached to all community colleges, through continuing education, negotiation etc. They were successful to a large extent but not beyond the basic services. But the author expected that they would go beyond the basic services and significantly improve the quality of services gradually by adapting due measures.

E M C Jansen et al. (2004) in their paper 'People with an Intellectual Disability and Their Health Problems: a Review of Comparative

Studies' tried to review a summary of studies on the prevalence of health problems in people with intellectual disability compared to health problems among the general population. The study was based on the international literature published between 1995 and 2002 and it was aimed to policy development for care of the mentally retarded persons. It was found the prevalence of epilepsy, skin disorders, and sensory loss and (increased risk of) fractures are more in the mentally retarded persons. This information helped the healthcare providers for people with mental retardation to take better care. But all the health problems of the mentally retarded persons were not easy due to problems to communicate with them. The authors concluded that the diagnosis of a lot of medical problems of the mentally retarded persons depend on the extent of knowledge, efforts and willingness of the medical doctors to spend more time for the mentally retarded patients.

E M C Jansen et al. (2004) in their paper 'Towards Improving Medical Care for People with Intellectual Disability Living in the Community: Possibilities of Integrated Care' said that due to deinstitutionalization several problems had raised in medical care delivery to people with intellectual disability. These problems were increased workload for general practitioners, a lack of active coordination and cooperation between health care professional. A major consequence was the incidence of untreated, treatable medical conditions. For better coping these inconveniences the idea of coordinated integrated care approach had been originated, which would coordinate health care, social care and related services. The authors tried to show the significance of this approach. They reviewed the relevant literature between 1995 and 2003. They found that the goals of integrated care were (1) reduction of fragmentation and discontinuation of medical care, (2) improving patient satisfaction and outcome, (3) supplying efficient and effective medical care. For these purposes multidisciplinary approach was advised. They concluded that even though the advantages of integrated care were theoretically well known, the precise applicability of this approach on people with intellectually disabled had still to be confirmed.

Ferdous (2009) in her 'Country Report on Intellectual Disability, Bangladesh' described in synopsis all about the state and care of the mentally retarded persons in Bangladesh. She said about the background, prevalence, risk factors of childhood disability in Bangladesh. Her mentioned risk factors were poverty, malnutrition, maternal illiteracy, maternal history of pregnancy loss, maternal



depression, small for gestational age, consanguinity, iodine deficiency, exposure to environmental toxin and pre and post-natal brain infection. She then gave information about the legislation, governmental policy, and national international convention on the issue of mental retardation. She named the service providers among which were government and non government organizations e.g. SWID, Bangladesh, BPF (Bangladesh Protibondhi Foundation) CRP, Tori Foundation GBSS, NCSE, etc. She said about the services which were running and future plan on this regard and as far the advancement achieved. The services were in the field of health, education, poverty eradication, preventing malnutrition, employment, recreation, special Olympic, community based rehabilitation and overall services. The author then recommended establishing a database for the mentally retarded people, allocation of necessary fund in the national budget, promoting inclusive education, providing training to more medical personnel on disability issues and giving all the required supports. She concluded that it should be done collectively to implement existing policies and overcome the gaps.

E M C Jansen et al. (2004) in their paper 'Integrated Care for People with Intellectual Disability: Evaluation of an Experts Network' described that in two experts networks were established to improve medical care for people with mental retardation living outside an institution. These networks provided integrated care by cooperation between general practitioners and other health care professionals to achieve continuity of care and correcting inadequacies in primary health care. In this study the samples were parents or primary caregivers of persons with mental retardation referred the experts network between 1 September 2004 till 1 May 2005(n=6). They were questioned about expectation and satisfaction of the services presenting symptoms and quality of care. The study showed that the parents or primary caregivers of the patients with mental retardation did not make use the services of the expert's networks. This was contrary to expectations of the parents, managers, policy makers. The causes for this were uncertain but it was assumed that the required preconditions were not duly addressed. Among these were lack of due remuneration of the network providers and having no insurance arrangements. Another cause was that the general practitioners and parents were not duly accustomed to this new arrangement. A third explanation was that the general practitioners considered themselves competent to solve medical problems of their mentally retarded patients and they thought it useless to refer them to the network experts. The authors concluded that further research to reveal the health care issues. The communication between health care

professionals should be increased and coordinated, adequately managed and should be upgraded which were too much essential.

P.J. Cushing (2003) in his paper 'Historical Review of Intellectual Disability' discussed the chronological history about the development of conception and approaches regarding deficits of care of the mentally retarded people. He said that definition of mental retardation changed from time to time and country to country and still it was going on. Though officially according to DSM-1V and ICD-10 it is named 'mental retardation' but in UK it is called 'learning disability' and elsewhere it is called 'intellectual disability'. The nature and process of services to these people also changed. Once a time these people were too much neglected. Then in early 1800s the era of institutionalization began with too much enthusiasm. This was continued up to 1960s. But due to many disadvantages then normalization and deinstitutionalization began from the late 1960s onwards and still it is the predominant idea. But this idea is also facing problems. People have stigma about mental retardation, its causes and avoid their responsibilities. Authorities are also giving less attention. There are lack of funds, support, training and all the needed arrangements and required manpower in this new model. The author then said about more understanding of developmental disabilities and a better coordinated, functional, adaptive and environmental approach in this regard. He then concluded that proper attention should be paid to change attitudes, values and beliefs of the caregivers and general public to continue and improve the situation.

Pamela Doty (2000) in her paper 'Cost-Effectiveness of Home and Community-Based Long Term Care Services' compared institutional versus community based care for the mentally retarded and those other people who require such services. First she described the condition of these services in various states of USA and then stated the findings. She found that (1) home and community based services were more cost-effective (2) narrow targeting, low average benefit levels and a strong emphasis on services would increase the chances of budget neutrality in home and community-based services (3) recent researches was leading policy makers more and more in the direction of emphasizing home and community services (4) availability of "at home" services had made it possible for most children with MR/DD to remain with their parents. Though substantial progress had been achieved in the way of community-based services, the author concluded that yet it was not possible to draw conclusion.

Scheerenberger (1983) in his paper 'A History of Mental Retardation' discussed the history from 45,000 years ago till the 19<sup>th</sup> century about mental retardation along with all other relevant features in a chronological order. He described a 'Neanderthal' man, and then some modern humans ceased being nomads. He then wrote about evolution of civilization through different stages throughout the world. First he described in a broad spectrum mentioning religion, philosophy, political and other issues, and then he narrowed his discussion to medical science, mental illness and mental retardation. In his paper he named the renowned philosophers, scientists, statesmen in the issues of mental retardation and related topics. He stated the evolution from ignorance to scientific era, from superstition to enlightened humanitarian thinking. He stated the history of various concepts and cares for the mentally ill and mentally retarded people.

Horwitz et al. (2000) in their paper 'The Health Status and Needs of Individuals with Mental Retardation' reported physical, mental, ocular, dental health conditions and services in these regards for the mentally retarded people. In the introduction they described the basic information regarding mental retardation, which may influence the required services. Then about physical health they said that like other people mentally retarded people suffer from chronic medical conditions e.g., cardiovascular diseases, cancer, cerebrovascular diseases, lung conditions and diabetes. In addition they may suffer from Down syndrome, autoimmune abnormalities, seizures, congenital cardiac conditions and thyroid diseases. But they get less adequate medical services compared to the general population. In respect of mental health they suffered less from substance abuse, but were more in anxiety disorders, depressive illness, psychotic disorders and personality disorders. Formerly these people lived and treated in institutions, but in current days community based services it was required to detect their problems through more extended arrangements. Regarding ocular problems they stated that early correction of ocular impairments ensure better functioning in education and social life for the mentally retarded children, adults and their families. Oral hygiene was also poor among the mentally retarded people, they suffer from caries, gingivitis and other periodontal diseases than the general population and the authors suggested efforts to improve their oral hygiene. Finally the authors recommended for due policy, system of care, and clinical care through improving leadership, continuity of care, increasing manpower and more in-depth reality based researches.

M. Miles (1996) in his paper 'Mental Retardation, Families & Education in Bangladesh, Introduction & Bibliography' reviewed the literatures and gave a bibliography on the condition of mentally retarded people in Bangladesh. He gave the history from 1770s onwards, the name of this region was then East Bengal, East Pakistan and now Bangladesh chronologically. He stated information about disability and evolution of services to the mentally retarded people from informal to formal stages. He showed a list of 20 disability surveys since 1961, gave an account of lives of Bangladeshis with mental retardation of rural and urban areas. He stated the development of various organizations for services of the mentally retarded people e.g., SCERMB (now SWID, Bangladesh), Bangladesh Protibondhi Foundation and many such other organizations. He concluded that the formal and professional services were getting only a little portion of the mentally retarded persons and majority of these people were getting services from their relatives and neighbors as per their level of knowledge and abilities. He commented that the position may remain nearly same the next 20 years.

Prater and Zylstra (2006) in their paper 'Medical Care of Adults with Mental Retardation' stated that mentally retarded persons were living longer and integrating more in the society, but they were getting less health services than the general population. They require continuity of care, maintenance of comprehensive treatment documentation, routine periodic health screening, and an understanding of the unique medical and behavioral disorders common to this population. There are lacking in their services due to inadequate compensation and deficit in experience among health care professionals in meeting the needs of this population. The authors then mentioned the specific health problems of the mentally retarded people and gave brief outlines of the managements of these conditions. They stated about respiratory problems, gastro intestinal disorders, challenging behaviors, neurological conditions, sexuality, sexually transmitted diseases and end of life decisions.

Sultana S. Zaman (1990) in a book named 'Research on Mental Retardation in Bangladesh' edited by her discussed nearly all about researches done on mental Retardation at that time. There were 13 articles in that book. In the first there were some original papers having findings on risk factors etiological factors & consequences of early and late interventions. Then it was stated the findings of various studies showing the attitudes of the parents, teachers and people towards mental retardation. Thereafter in the last few chapters it was

discussed other disabilities and autism which were co morbid along with mental retardation. In the last chapter it was given an epidemiological assessment of childhood disability in Bangladesh. This book was a pioneer work in the field of mental retardation in Bangladesh and still it is giving light in this area.

Mamun (2011) in his 'Country Report: Bangladesh, State of the Persons with Intellectual Disability in Bangladesh' stated elaborately the programs and activities of SWID, Bangladesh (Society for Welfare of the Intellectually Disabled, Bangladesh), of which he is now President. Its programs included education, Special Olympics, advocacy, rehabilitation, home/residential services, guardianship and life-long care. He then described the whole picture of latest disability situation in Bangladesh mentioning government and non government initiatives. He stated about national coordination, disability policy, 'Disability Welfare Act-2001', medical care, employment and all relevant issues. He gave many recommendations; of which important were regarding special education which should be included in regular educational institutions medical persons should be trained on disability issues, employment policies need to be adapted to accommodate services for persons with mental retardation.

Girimaj et al.(2001) in their book 'Mental Retardation : From Knowledge to Action' discussed about primary issues related to mental retardation e.g. historical background, myths, misconceptions about mental retardation, development of children, some facts and figures, causes of mental retardation and then suggested what can be done and how to prevent the condition. They said for organized services from professionals of many fields, families, governmental and non-governmental organizations and the society as a whole. They commented normalization process should be upgraded, mental retardation should be an integrated part of society, they should not be isolated, segregated or discriminated and societies have to work together. They recommended extended medical services, along with its individual components e.g. prevention, diagnosis, treatment, management of general as well as special medical problems, diseases and complications. They advised about parenthood and also about some intervention measures for the mentally retarded persons e.g. behavior modification technique, social skill training, special education and involving them in all activities. They at last suggested what can be done by the community, health sectors along with mentioning the experiences of various countries.

D. A. Khan (1996) in his paper ‘Childhood Disability’ said that most of the disabilities are preventable. He mentioned the initiatives of UNICEF from its onset in 1946. In 1980 UNICEF adopted an expanded strategy for preventing disability and addressing the special needs of children with disabilities. It was began universal immunization, primary health care, safe water and sanitation, training of others and community health workers. The role of malnutrition, specifically micronutrients deficiencies was detected in causing physical and mental impairment. Role of vitamin A, iodine deficiency was then addressed. In 1990, 71 Presidents and Prime Ministers committed at a World Summit for children to reduce child death and disability from preventable diseases and malnutrition by the year 2000. The world is witnessing the fulfillment of that commitment. The author then described the Bangladesh scenario. He mentioned the causes of disabilities in Bangladesh e.g. malnutrition, illiteracy, poverty, superstition etc. He then suggested the possible measures to combat the situation, e.g. immunization, control of micronutrient deficiencies, early diagnosis of disability, community based rehabilitation, full access for children with disability to health, education and recreation facilities etc. He then concluded that with successful implementation of all the program in Bangladesh this country will enter into a brighter tomorrows.

Islam et al., (1993) in their paper ‘Socioeconomic Status and the Prevalence of Mental Retardation in Bangladesh’ reported a population –based study of the prevalence of mental retardation among 2-9 years old children in Bangladesh. It was screened more than 10,000 children for mental retardation and other disabilities. All children having positive screening results and random sample were referred for clinical evaluation. The prevalence rates were 5.9 and 14.4 per 1000 as severe and mild mental retardation in this population respectively. They concluded that mild mental retardation was strongly and significantly related with socioeconomic status and it is consistent with the studies of developed countries, whereas severe mental retardation was not significantly related with SES, rather a weak relation with SES.

Durkin et al., (1994) in their paper “ Measures of Socioeconomic Status for Child Health Research: Comparative Results from Bangladesh and Pakistan” reported that had examined the reliability and validity of socioeconomic status of several hypothesized indicators for use in epidemiologic researches particularly in case of children’s health of less development countries. Population-based

surveys of child health and disability were done in Bangladesh and Pakistan by using standard questionnaire. The questionnaire was designed to measure four domains of household socioeconomic status: wealth, housing, parental education and occupation. It was found from factor analysis of the survey that housing and wealth as distinct domains in both countries. Parental education and wealth were correlated with housing and wealth. From bivariate logistic regression analysis it was found that though 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. The authors concluded that along with multivariate results demonstrate the importance of including multiple measures of distinct domains if the research aims include investigation and/or control of the effects of socioeconomic status on health in diverse populations.

Conachie (1996) in her paper 'Families of Disabled Children' said about partnership regarding disability services. He described differences in families in respect of structure, resources and coping strategies. It was suggested how to design intervention. He told about legislation, which aims for empowerment of families, consultation and a broad support for professionals. It was said about assessment of the child and families for overall needs, resources, required supports and services. At last he recommended for due training and skill in this regard.

Banu, Islam & Sultana (1996) in their paper 'Vocational Expectations of Parents and Teachers of Mentally Retarded Children' described the results of an study of which the respondents were 80 parents (Mother 40, Father 40) and 5 teachers, 40 parents were of 20 mentally retarded children who were in special education school and 40 parents were of 20 mentally retarded children not attending school. They were supplied questionnaire to investigate vocational expectations. The results showed that mother had highest vocational expectations than those of the fathers and teachers. Results also showed that irrespective of training there was significant difference between fathers and mothers. It was also found that the parents whose children were attending special education had more positive belief than those parents whose children were not attending school.

S. Zaman (1996) in her paper 'Necessity of Developing Special Education and Training Programs on CBR in SAARC Countries' reviewed the situation of special education and CBR training program in SAARC countries. She described the necessities for training of professionals and paraprofessionals in disability concern what should be the contents of the courses for training. She mentioned about normal child development, different type of disabilities, mental retardation, CBR program, cost appliances, referral and follow up. She then said about leadership in disability program and finally suggested and recommended for more structured special services including CBR program.

Mehta and Dave (1996) in their paper 'Establishing Referral System in Care of Mentally Retarded Children in Community-Bombay Experience' described about population screening (Bombay Model) for detection of mental retardation, then problems and diseases of these people and referral for genetic counseling and other measures. The authors described the necessity for identification, prevention and rehabilitation of the mentally retarded child / person, in a community based approach. In Bombay Model the people were divided into various sectors and they were screened by medical doctors, nurses, multipurpose workers (MPW) and community health volunteers (CHV), who were well trained in this field. They arranged workshops and provided information to the parents, family members and people also. In the 1<sup>st</sup> year, 512 cases were detected of which 251 cases (49%) were preventable. The preventable factors were environmental and genetic (H/o miscarriage, still birth, neonatal death etc.). The other causes were genetic (36.7%) e.g. Down syndrome, Microcephaly, Inborn Errors of Metabolism. Non specific mental retardation constituted major group of 73 cases (14.3%). Instead of western style of genetic counseling it was termed "Community Based Genetic Counseling" to serve these people. In this system only high risk cases were done laboratory/genetic tests which reduced cost in a low level of socio-economic society. In other cases the care system was mainly education, training and rehabilitation. The authors concluded that Bombay experience can be replicated in developing countries which ensures best use of available resources offering effective health services.

Parikh et al. (1996) in their paper 'Etiological Factors in Mental Retardation: A Study of 5000 Cases from India' discussed their study of 5000 cases in India to elicit the causes of mental retardation. The study took place at the Genetic and Developmental Clinic, Smt.



Motibai Thakersey Institute of Research in the Field of Mental Retardation, Sewri, Bombay. All cases were assessed by a multi-disciplinary team and were subjected to a detailed clinical evaluation, including a through pre-natal, natal and post-natal history, attainment of developmental milestones, pedigree charting with family history of mental handicap, epilepsy and other illnesses, physical and mental examination. Out of the total 5,069 cases analyzed, the etiology was ascertained in 3,216 (63.4%) cases while in the remaining 1,853 (36.6%) cases no definite cause was pinpointed. Prenatal factors were responsible in 1212 (23.9%) cases, prenatal factors were responsible in 1051 (20.7%) cases and post-natal factors were responsible in 953 (18.8%) cases. Thus the environmental retardation was 2171 (42.8%) and 1045 (20.6%) were of genetic causes. The commonest environmental causes were Birth Asphyxia, CNS infections, epilepsy, prematurity and low birth weight. The commonest genetic causes were Down syndrome and Fragile X syndrome. The authors then suggested avoiding consanguineous marriages or marriages between partners having families with mental handicap of genetic causes. They also advised about nutrition, efficient obstetric care and vaccination.

Ferdous and Sultana (1996) in their paper ‘Medical Aspect of Cerebral Palsy in Shishu Bikash Clinic of Bangladesh Protibondhi Foundation’ discussed about the risk factors causing cerebral palsy and other such problems from their findings in Shishu Bikash Clinic of Bangladesh Protibondhi Foundation during the period of January to December 1993. Most important component of initial evaluation of child was developmental delay or mental retardation. They were assessed by taking medical history, family history, developmental history by Denver Developmental Screening Tests (DDST), IQ test by Wechler Intelligence Scale for Children (WISC-R). Out of 279 such children 38.70% were of cerebral palsy. The causes they found were Birth asphyxia 51.85%, Neonatal Convulsion 10.18%, Preterm 9.25%, Febrile convulsion 6.48%, Epilepsy 3.70%, Neonatal Jaundice 2.77%, Chromosomal defect 0.9%, Consanguinity 0.9%, Hypothyroidism 0.9%, Post encephalitis 0.9%, Twin Pregnancy 0.9%, Placental insufficiency 0.9%, Forceps delivery 0.9%. Finally they concluded that as “Birth Asphyxia “as a major cause of cerebral palsy causing childhood disability. So antenatal checkup, neonatal and perinatal care should be improved. Then the incidence of Birth Asphyxia will be reduced and thus mental retardation and other sequelae can be prevented.

Parikh et al. (1996), in their paper 'epidemiological and Cytogenetic Study of Down Syndrome in India' discussed the results of cytogenetic study of 550 clinically diagnosed children having Down Syndrome, seen at the Genetic and Developmental Clinic Smt. Motibai Thackersey Institute of Research in the Field of Mental Retardation, Sewri, Bombay, from 1974 to 1994. The study was carried out to determine the epidemiological factors, particularly maternal age, consanguinity was significant. Religion, socio-economic factors were not so significant. In cytological study it was found Trisomy 21 in 89.4%, Translocation 9.3%, Mosaicism in 1.3% cases. The authors concluded that by knowing the origin of Trisomy 21 the persons with Down Syndrome will get more help and care.

Black (1996) in his paper 'Urbanization and Childhood Disabilities' said that as urbanization increased, it was associated with industrialization and economic development, but at the same time children were confronted with formidable challenges to their health and development. Although the threats from infectious diseases and specific nutritional deficiencies have been reduced, new problems emerge from overwhelming problems of poverty, population expansion and environmental stressors. The author suggested multi factorial solutions addressing intervention at the level of community, families, parents and children to secure health and dignity for children of the future.

Dave et al. (1996) in their paper 'Inborn Errors of Metabolism in Persons with Mental Retardation' discussed the results of the study carried out at the Genetic and Medical unit of Smt Motibai Thakersey Institute of Research in the Field of Mental Retardation, Sewri, Bombay, India. The study included 922 children with mental handicap having complains of mental sub normality and speech. Among them the cause was detected in 663 (71.9%) cases. Out of which 412 cases had environmental factors, 251 cases had genetic origin. Chromosomal abnormalities was found in 157 cases (30.7%) with highest number of Down Syndrome. Identifiable genetic syndromes were present in 78 cases (15.26%). Inborn errors of metabolism was found in 16 cases (3.13%) with the maximum number of Mucopolysaccharidoses cases. The child with Phenylketonuria showed high level of phenylalanine in plasma and urine samples. Out of 16 cases of inborn errors of metabolism 12 showed autosomal recessive mode of inheritance and 8 of them showed presence of consanguinity, 7 cases had family history of mental Retardation and 4 of those were siblings. The authors inferred that knowledge of the

causative factors help in dealing with the problem more appropriately and with definite course of treatment, therapy and intervention.

Bhanumati et al. (1996) in their paper 'Study of Fragile X Mental deficiency Syndrome in a Population of Mentally Handicapped' described their study of 350 individuals from February 1987 to October 1994. The individuals were from profound mental retardation to normal intelligence. All cases were subjected to a detailed clinical examinations, psychometric assessment, biochemical tests and radiological investigations and all etiological causes were ruled out. Cases were selected for chromosomal analysis based on these criteria. Out of 350 cases 44 (12.5%) were positive for fragile sites on the X chromosome. These findings also showed familial background. Appropriate genetic counseling was given to the families. Though there is no cure for fragile X syndrome, the authors suggested and recommended a team approach to improve their behavior and developmental progress. Multi modal treatment, involving a special educationist, occupational therapist, psychologist and pediatrician is generally effective for pre pubertal males as well as significantly affected females. They also advised about diagnosis on amniocentesis, chorionic villous sampling combined with DNA marker analysis, which will prevent this common inherited form of mental retardation.

Zinkin (1996) in her paper 'Progress in Community Based Rehabilitation (CBR)' described experience and progress regarding community based rehabilitation (CBR) for the disabled people. Due to negligence by the common people, during the past 15 years, the disabled people and their parents formed their own organizations. The author said that these organizations, international, national and local are crucial in the progress of community based rehabilitation (CBR). There are so many programs and projects according to the idea of community based rehabilitation. The thriving programs had often different starting points such as health, education or social services. Some had initiated by international organizations, government, NGOs and charities and some by professionals for disabled people or parents, which had difference as well as convergence in many areas. WHO was pioneer in this field. Its program was based on primary health care infrastructure and was easy to be applied in the community. Then the 'Guyana Community Based Rehabilitation Program', 'Project Projimo', 'Uganda Community Development Assistance Program' 'ADD-India' etc. were important to be mentioned in this field. The author then concluded that CBR was a process which may differ in the contest of each country and community, and same experience couldn't

be shared by others. It should be learned from mistakes and failures, not only from successes. To progress discussion should remain open.

Tuli (1996) in her paper 'Reaching the Unreached through Community Based Rehabilitation' described the aims and objectives of community based rehabilitation and thereafter its framework, approaches and strategies. She said about attitude, empowerment, transfer of knowledge, self help skills, developing rehabilitation services. She mentioned the components of CBR program, about its implementation. To implement she said it required various models e.g. medical, vocational, educational, social. Then it was needed referral chain, inclusive training, funding, residence, dissemination of services, evaluation and monitoring, and finally integration, placement, income generation, sustainability and follow up. The strategies were community preparation, integration, formation of agencies, fostering community involvement, assessment of resources, empowering, funding by cash or kind. She also discussed about the needs for research and training and finally suggested for synthesis of needs and manpower available, proper orientation, planning and liaison.

Krishnaswamy (1996) in her paper 'The Evaluation of the Parent as a Co-teacher, Co-Therapist and Self-Advocate in Early Intervention Programs' reviewed the role of parents in the development of the child. She mentioned various historical Studies. Among those 'The Classic Studies of Skeels and Skodak from 1930-1949, USA', 'The Toddler Research and Demonstration Project, 1970, USA', 'The Abeedarian Project, 1979, USA', 'The Milwaukee Project, 1975, USA', 'The Head Start Program, Begun in 60s, USA', 'The Portage Project, 1969, USA', 'The Madras Project, 1968, India'. From these studies the author observed that, early intervention, participation of the parent, family oriented programs, lower children to teacher ratio were important factors for better impact on the children regarding their development. He then suggested about individualized program plan and intervention strategies, where he said that mother would first train her own child herself being guided by special teacher. That mother would then teach other mothers and children, because throughout the country not so many teachers were available. In this way the author proposed other strategies on home – based programs. She finally concluded that parental involvement in early involvement program showed definite quantitative and qualitative improvement in the child.

Malhotra (1996) in her paper 'Efficiency of Selected Norm-Referenced, Curriculam-Referenced and Criterion-Referenced Tests for Assessment, Record-keeping, Program-Planning and Development of Curriculam for Persons with Mental Handicap' described the results of the educated strategy of profiles and outcomes in studies to achieve certain skills. The study aimed to train the teachers to keep detailed cumulative records for each child and to plan I.E.P.'s on the basis of these records. The other objective s were to use the selected tools for developing I.E.P's of special children with the help of teachers to guide their psychosocial, cognitive and independent living skills for integration into the community life. A pilot study was done at Okla centre by Delhi Society for the Welfare of the Mentally Retarded Children (DSWMRC) New Delhi. Individual profiles were prepared for over 200 children by using AAMD Adaptive Behavior Scale school-Education (ABS-SE) and also other selected tools. All teachers of the centre were then trained. All respondents attended the initial training workshops and were equipped with skills to use the tools. The results showed that there was need for some more training for certain points and about using equipments as they can be confident to teach the children and feel secure. The author concluded that in service training and continued co-ordination between interdisciplinary team of professionals for planning a comprehensive management plan for a particular child was highlighted.

Banerjee et al. (1996) in their paper 'Genetic Counseling in Developmental Disabilities' reviewed the overall aspects of genetic counseling in developmental Disabilities, specially for mental retardation and their experience in this field. They said that basic information needed for genetic counseling was history and pedigree constructure. Then it needed various methods of prenatal diagnosis were amniocentesis, chorion villus sampling, ultrasonography and radiography. The author s mentioned their experience of various laboratory tests for 997 cases during the period of 1969-1993. They found that environmental causes were more in mental retardation (41.22%), and then genetic (32.79%) and less were idiopathic (25.97%). In conclusion the authors said that as due laboratory facilities were not affordable in wide range, mass awareness and education was must to prevent genetic causes of mental retardation.

Fleming (1989) in her paper 'Health Services to Children with Mental Retardation in the Community, Schools and Home' described and analyzed the factors in the Health Care Delivery System and factors in the society which were concerned with the medical care of the mentally

retarded children. In the Health Care Delivery System she mentioned two factors, one was the cost of the hospital and other relevant services and another was technological advances which had revolutionized diagnosis and treatment of some conditions, liability claims and increased cost of malpractice insurance. Among the factors in the society she mentioned (1) average increase of age in the people (2) cultural diversity among the population (3) more women in the work force. After analysis she suggested to enhance deinstitutionalization, more economic and technological development, combination of family, health professionals and public spirited working together.

De Ore (1989) in his paper 'General Family Role, Financing and Trust Planning in Community Integration, Now and the Future' reviewed the works of National Foundation for the Handicapped which was working for 26 years. The goal of this foundation was to bring forefront the need to make the community and country aware of the problems associated with mental retardation as well as other disabilities. Their activities ranged from brain research to genetics, to the everyday issues surrounding different causes and problems faced by parents of disabled children and adults. The foundation was getting co-operation from the administration as well as from the public and private sectors. Still they were facing many problems e.g. less amount of dollars than it required, legislation limitation etc. The foundation had established Self-Sufficiency Trust (SST) to overcome the monetary problems. This foundation was used for various welfare activities of the disabled individuals e.g. for social services, rehabilitation and remedial services, education, recreational programs, respite services, habilitation service and training programs to assist disabled persons in managing activities of daily living. The trust was trying to collect fund by many ways. The foundation was continuing its effort to achieve the goals.

Sajevic (1989) in his paper 'Promoting Maximum Community Integration through People' reviewed the past 20 years of community integration of the disabled persons. The author said that many of the people who were disabled benefited from services and support that facilitated a full and active community experience. Services and support had been developed to offer housing, education, employment, recreation and health care options. The new term developed 'tailored to individual needs'. The problems in this process were lack of personalization of staff, less availability of competent staff, significant demands and stress, lack of 'team' feeling, lower level of marketing, low job satisfaction. The author then recommended for 'people

centeredness' i.e, ensuring participation of the people and maximum utilization of the human energy and potential.

Doerer (1989) in her paper 'Public/ Private Partnership Working together to Provide Employment' expressed her experience of working for the mentally retarded persons regarding their employment. She termed the initiative combining public and private partnership as 'working partnership'. Then she identified the roles each partner assumes with major categories of public and private including their strengths and needs. Through projects and proposals she illustrated the examples of cost-effectiveness and innovative methods of cooperative community efforts which focused on employment of people who were mentally retarded. Finally she recommended for increased facilitations of positive relationships with private enterprise.

Marchand (1989) in his paper 'Transportation Considerations for Citizens with Mental Retardation' discussed about the lacking regarding transportation facilities for the mentally retarded persons especially for the profound category. He said that there was no national policy on transportation for people who were mentally retarded. There were many ways of transportation e.g. private, public and personal. But it was not clear who was responsible pin pointedly in this regard. The author proposed for training of transportation workers to handle special problems of the mentally retarded persons and to arrange duly for them mainline Transportation as well as door to door para-transport type services.

O'Tuel (1989) in his paper 'Integration of Children with Mental Retardation into Public Schools' reviewed the situation of inclusion of children with mental retardation into public schools. He said that the objectives of inclusion into public school for the mentally retarded citizens were as they could learn to support themselves, to contribute to society and to be accepted by others. In this respect awareness was crucial part of responsibility for the school authority to improve community –school relation, school- board relation, school morale and image building. The authority of school should visit the mentally retarded student in their learning environment; talk with them, with other students, teachers and parents. The nature and needs of the mentally retarded students should be understood. Finally the author concluded that inclusion of the mentally retarded children in the public school will ensure integrated society, where these citizens can live, learn, work and play successfully and it should be given due priority.

Schleien (1989) in his paper 'Community Leisure Services and Persons with Mental Retardation' reviewed the state of leisure and recreation activities in the community. He said from his observation that there was a substantial gap between the services needed and services available. The recreation programs offered for school aged children, for example, had focused on a small set of activities so these were monotonous and stereotyped. He also mentioned that it was required a least restrictive environment (LRE) to design and delivery of recreation and leisure program for persons with developmental disabilities. He stated the importance of communications and collaborations across individuals and agencies for integrated, accessible community leisure services. He suggested being responsible all of the public park and recreation agency and staff, the therapeutic recreation specialist, care providers, consumers and other key players must assure active roles in this process. He then concluded that integration and the development of accessible community leisure services must be approached carefully and systematically as if all citizens, with and without disabilities, were to receive successful community leisure experiences and realize a descent quality of life.

Cohen (1989) in his paper 'Respite Care from an International Perspective' reviewed his experience of respite care. He said that respite care developed from mid 70's, due to deinstitutionalization. Parents, rather than professionals, were the true originators of this service. In 1978 the Louisiana Developmental Disabilities Council found that 68 agencies serving individuals with developmental disabilities in that state reported receiving requests for care from families although only 16 offered this service. Professionals had in fact a large gap to develop these services after deinstitutionalization; they were ignorant to the needs of families, leaving many families to be strained beyond their coping capacities. By 1980 respite care had gained the recognition of professionals as a sorely needed service. But still it was not extended as per requirement. In conclusion the author said that the respite care was a concept of shared care, it might be of various types and should be accessible to all families having disabled children.

Barber (1989) in his paper 'Planning for Economic Security' stated that the delivery of services to people with disabilities cannot be solely the responsibility of government or families, it must be a community responsibility. It should be noted that resources were available in churches, clubs, civic organizations, neighborhood associations and all groups of life and those should be utilized to serve the disabled



people. The new era of service emerged was to enhance economic and social security. Job training and employment, adult service plan, sheltered to integrated employment, Structured Training and Employment Transitional Services (STETS), Manpower Development Research Corporation etc. were developed and were still continuing in many aspects. Moving to apartment and other small living arrangements were taken for greater community integration. He then concluded and recommended that economic security must be conducted in a larger context assessing the needs, with proper planning for the mentally retarded persons and their families.

Janicki (1989) in his paper 'Transition from Work life to Retirement for Older Persons with Mental Retardation' stated that as the life span of the whole population was increasing it was also such in case of mentally retarded persons. This increase in age was giving rise to many new problems e.g. demands for services, special attention, old age diseases, family troubles, community residential situations, need for retirement oriented programs. To give services it was also facing many barriers e.g. 'handicapism' i.e. negative attitudes to the disabled, limited economic facilities, inexperience and fear. The author concluded and recommended that information, education and training should be available to the aging mental retarded agencies. Interests and needs of the older persons with intellectual disability should be taken as agenda for all the authorities concerning these people's services.

Clenda Davis (1989) in her paper 'Citizen Advocacy' stated that whole community should be involved in the process of integration of the mentally retarded persons in the society. It required citizen advocacy which could create and support relationships between citizens of a community and the mentally retarded people. It should be used the words 'home, neighborhood, church, school and job.' She concluded that people who lived in the community should be involved in the services and it required no special training, all the people can be engaged. She advised to trust on the competence of the community.

Roos and Mc Cann (1977) in their paper 'Major Trends in Mental Retardation' stated the past and future aspects of mental retardation regarding its conceptions, philosophies, attitudes and care for these people. They described that the retarded children of their time were better in their condition than their predecessors. In the past the services were designed as these people were sub human organism, the menace, the object of pity, the eternal child and the diseased organism.

Dependency, safety, cleanliness, and comfort were emphasized, and the situation was a hopeless one. Then the current trend developed which was 'the developmental model', creating positive view i.e. control over environment, behavior development and maximizing human qualities of the mentally retarded people. Normalization, individualization and self-actualization were begun to be thought for the retarded persons. Consumer advocacy on behalf of the retarded citizens which was rooted in 1930's further developed. The authors expected that next technological development might greatly improve the condition of retarded persons. They stated space technology, prosthetic environments, telemetry, biofeedback; biomedical science might benefit the lives of these people. They concluded that the future of the retarded persons would be certainly influenced by socio cultural and technological changes that dependent on the endeavor of pioneers in all spheres of life.

Marriot and Gooding (2007) in their paper 'Social Assistance and Disability in Developing Countries' stated that social practices was important in reducing poverty and developmental disabilities and it required social assistance in the form of cash and in-kind transfers. Disabled peoples specially required this form of supports. The authors studied this aspect in developing countries. They explored the perspectives of key stakeholders, and using the information available on both mainstream and targeted social assistance programs, examining their characteristics, and ability to reach and benefit disabled people. They said that social assistance was an empowering investment, it was an income supporting, it reduced dependence, and it was an important way of solution regarding education, employment and many other issues. It should be arranged by government, non government and international organizations. The social assistance in many cases should be unconditioned and it might also be conditioned. The barriers in social assistance were limited resources, complex administrative system, poor governance, physically inaccessible services, low awareness etc. In conclusion the authors recommended for a strong right-based framework, participation of the disabled people, empowerment, more information, disability data and research.

Reports of many other research works in the field of mental retardation are available in the journals, books and internet WebPages. But recently it was not assessed how the parents, family members and concerned persons are assessing the present medical and psychosocial care situation in Bangladesh.

With the introduction of EPI programs and development of medical facilities in the country, the life span of the mentally retarded persons have increased in this country. Therefore, the needs and perception of the concerned family members are also changing. To undertake suitable programs to uplift the condition of these persons and to amend the policy programs this research is an attempt with the following objectives.

## **Objectives of the study**

### **General Objective**

The General Objective of this study is to assess the current status of medical and psychosocial care of the mentally retarded persons in Bangladesh and to suggest ways and means for its betterment.

### **Specific Objectives**

- a) To study the needs of the mentally retarded persons in relation to medical care.
- b) To study the needs of the mentally retarded persons in relation to psychosocial care.
- c) To assess the present condition of services for these needs.
- d) To assess its drawbacks and identify the specific problems.
- e) To suggest ways and means to uplift the conditions.

### **Significance of the Study**

In Bangladesh it is seen that most of the mentally retarded persons are living without care. People and the concerned authorities are not duly conscious and lack of proper knowledge is predominant. The existing medical and psychosocial cares are very poor in relation to the enormous needs. The services are not duly coordinated. There are many associated problems e.g. finance, education, rehabilitation etc. Scarcity of skilled and trained professionals causes many trials and errors with the mentally retarded children. The related programs need to be systematized and scientific. The findings of this study will help the concerned persons to overcome these shortcomings.

## **Chapter II**

### **Methodology**

The researcher mainly followed case study method in this study. Observation and free discussion methods were also used to enter into the depth of the cases. The researcher didn't follow any hard and fast procedure; rather he tried to understand the situation and to know how to improve it through various methods and procedures.

The researcher observed all the cases for a long period in different conditions. He had free and informal discussions with the parents/guardians in relation to medical and psychosocial care of the subjects.

The study also included

- Background data of all the mentally retarded persons.
- Both structured and unstructured interview.

Field notes were maintained properly. This study also required case histories, personal health records and all available medical documents of the subjects.

Mainly the Mothers of the mentally retarded persons were the respondents in this study as they were found well aware about the condition of the subjects and could answer all the questions of the researcher. Concerned medical doctors, field level NGO workers, psychologists, psychiatrists, social workers, Government officials were also interviewed on related issues.

The researcher established contact with the families of the subjects and studied them mainly at their home. He visited the subjects on a regular basis during 2009-2014. He requested the families to inform him all the medical and psychosocial problems of the cases and what care they were provided for these problems. He visited the subjects regularly and repeatedly to know in depth about them and about their problems and care. During last few years he came in close contact with them and their families through telephones also. Some of the subjects and their parents frequently visited the researcher and yet continuing the visits.

The researcher mainly observed the subjects and took their medical and psychosocial histories, interviewed them and their family

members. He allowed them to talk by themselves about their needs, problems, cares and expectations. When he intended to know something special, he asked questions. He discussed his observation and findings with the relevant professionals and experts. He then informed all these to his supervisor, discussed with him and tried to enter into the depth of the study.

He recorded his findings and observation in his note book. Finally he developed the questionnaire and collected the answers from the respondents. He then performed data processing and analyzed the data.

**Study areas:** Dhaka city and Rajshahi district were selected as the study area. The researcher made contact with Shishu Hospital of Dhaka, Bangladesh Protibondhi Foundation, SWID Bangladesh, SIVUS Institute, Child Development Centre of Rajshahi Medical College Hospital. He visited few villages of Rajshahi district. Thereby he came in contact with the mentally retarded persons, their families and relatives and collected the data.

### **Justification of the selection of study areas**

The researcher as a physician has observed that the medical facilities and treatment seeking behaviour are almost same throughout the country. Transport facilities to come to the medical centers from the residence, interference of the decision makers as well as the village physicians, socioeconomic condition, etc. are almost similar in the entire country.

The researcher tries to justify his study area selection through the following observation.

For qualitative data of a population with homogenous culture, language and ethnicity in a very small but populous country an intensive study of a typical population in any place is enough. It is expected that repeating the procedures in other places all over the country will give the similar findings. It is due to as they have almost similar traditional beliefs, socioeconomic conditions, cultures and practices. This is particularly true for Bangladesh.

Unlike India, Russia or other very large countries (where number of population groups inhabit in different areas and have individual own cultures), Bangladesh is a small country with tiny area of 147.570 Sq.

Km. only. Bangladesh has almost homogenous population in respect to religion, linguistics, socioeconomic conditions and traditional beliefs etc. Typical population groups (98% Bengali) in this country are of homogenous characteristic population groups except a few Biharies (400,000) and some small tribal groups. With a population density of 864 persons per square kilometer (1998) Bangladesh is one of the most densely populated countries in the world. Most of the people live in thousands of small villages that blanket the country. Only about 20-22 percent live in the urban areas.

Unlike other countries, there is only one language (Bangla) among all the inhabitants.

Sometimes with negligible local mainly Bangla is the local newspaper language throughout the country. Text and other books are published in the only local language (Bangla). Radio and Television media broadcast programs in the Bangla. So, information and knowledge disseminations and all communications are in the same language (Bangla).

Religious proportion of the typical population groups is almost same in all parts of Bangladesh, i.e. Muslims, Hindus, Buddhist and Christians. Literacy rates are almost similar in different regions. Similar political trends are observed. Almost all people have similar appearance, height, hue and other anthropological aspects.

From the above facts it is expected that findings from and the selection of respondents only in Dhaka and Rajshahi cities and some villages of Rajshahi district will be similar if a nationwide survey is done.

**Sample size:** From the available records of the concerned organizations, the researcher purposively selected 90 cases. During selection process he considered the nature and seriousness of the handicapped conditions of the cases.

He also considered the socioeconomic condition of the cases. He included only those cases whose parents, especially the mothers, are literate or at least possess primary education.

At the beginning, the researcher selected almost 150 cases, but it was found that some parents did not continue long term discussion with the researcher or did not inform him about the changing problems of the

cases. Therefore, the researcher excluded some cases and this report is based on 90 cases.

Total sample size was 90. Among them 30 were of Dhaka city, 20 were of Rajshahi city and 40 were from three villages of Rajshahi district.

The parents were the respondents of this study. On the basis of their long term discussion, answers, opinions, etc. some quantitative data were analyzed as shown in chapter IV of this thesis.

### **Data collection technique**

#### **(A) Technique of secondary data collection:**

Literature survey has been done for collecting secondary data and it was a continuous Process. The researcher reviewed the related journals, papers in websites, published and unpublished study reports, scholarly books, documents of government and non- governmental organizations, census and survey reports etc. He also consulted with many experts in this field. They gave opinions about the research. They provided information about the problems of the mentally retarded persons and how to improve the situation related with their care. Thereby the researcher achieved much new knowledge. The discussion with them was informal and without any structured questionnaire.

#### **(B) Technique of primary data collection:**

From the beginning of his study the researcher started to visit various centres, organizations, institutions, hospitals etc. concerned with the services for the mentally retarded persons. At the same time he was involved with reviewing literature, books, news items, and websites and consulted and communicated regularly with his supervisor. He visited the central office of SWID, Bangladesh (Society for the Welfare of the Intellectually Disabled, Bangladesh), at Eskaton Garden, Dhaka. He observed the mentally retarded persons there, consulted with the officials, care takers and also studied at the libraries of these centers. He visited Bangladesh Probindhi Foundation, Mirpur, Dhaka, where he met the executives of the foundation and other officials. He saw the laboratory, classes and all arrangements present there. He also consulted with them. In Rajshahi, the researcher visited 'Asha Buddhi Protibondhi Biddaloy' of Ponchoboti, Rajshahi. He visited there the teachers, organizers and the mentally retarded children.



The researcher visited Child Development Centre, pediatrics unit, psychiatry department of Rajshahi Medical College Hospital, Child Development Centre of Dhaka Shishu Hospital, Dhaka, Child Development centre of National Institute of Mental Health, Dhaka and many other organizations. The researcher visited many houses of the mentally retarded persons in Dhaka and Rajshahi cities, whereby he knew the situation keenly.

The researcher visited some villages of Rajshahi districts. He there consulted with the family members, relatives, neighbors of the mentally retarded persons. Thus he got a deep insight into their medical and psychosocial problems and the condition of care for them.

The researcher also consulted with the previous researchers in this field. He got a lot of knowledge from them. He consulted with the experts and officials before beginning the fieldwork.

The researcher is a psychiatrist; so many guardians come to him to take advice about their mentally retarded children. In this way he is acquainted with their problems and care for them.

Having these knowledge and experiences, the researcher also prepared a questionnaire and began the field works. The field works continued for several years in the study areas in Day Centers, Clinics and residences of the mentally retarded persons.

### **Data collection instrument (The questionnaire)**

Though it was mainly the observation and discussion, some information were collected by using semi-structured questionnaire along with socio-demographic information. It was in Bangla for the convenience of the respondents. The questionnaire and its English translation are attached in the Appendices of this thesis. The questionnaire was designed to collect some important data on medical and psychosocial care of the cases. To gather data about medical care the questionnaire possesses the following areas of interests:

1. Questionnaire about medical care regarding prevention of mental retardation.
2. Questionnaire regarding medical care for those diseases which were interrelated with the condition of mental retardation.
3. Questionnaire on medical care for those diseases which also occur among all the people.

As mental retardation is not curable, preventive measures are the most important part of the medical care. It begins before the birth of the mentally retarded child. So the questionnaire included genetic / hereditary conditions, maternal and fetal care to assess the measures to prevent mental retardation.

Some diseases occur as a part of specific causes of mental retardation. In this regard some questions were included to search these conditions.

The common diseases that occur among all other people were also searched among the participant cases. As mentally retarded people can't express their condition, so the questions related with these diseases are of much important to compare their status with other people regarding illness as well as their care.

To collect data on psychosocial care the questionnaire had the following headings:

1. Psychological (Emotional) Problems
2. Education
3. Earning
4. Housing
5. Social life
6. Recreation

The problems of the mentally retarded persons are enormous regarding their psychosocial aspects. Normal people can get their living arrangements and emotional support by their own efforts. But for the mentally retarded people it is hard to arrange these by their own capabilities. Now a day due to improved EPI program and better medical facilities the mentally retarded people are living longer. So their parents can't take their care lifelong. It is a burning problem for them as well as the society to cover their whole spectrum of care. It should remain clear to all about these responsibilities and these issues were also included in the questionnaire.

Then the respondents were asked about the role of various authorities and organizations in the field of medical and psychosocial care of the mentally retarded persons in Bangladesh. Finally the respondents were asked to evaluate the current status of medical and psychosocial care of the mentally retarded persons in Bangladesh. At the end there was a provision to give free opinion of the respondents on the overall aspects of the issue.

**The respondents:** In Dhaka city the researcher meet the families of the respondents directly with the help of the trainees of the Child Psychology center of Dhaka Shishu Hospital. He also went to the Bangladesh Protibondhi Foundation, SWID Bangladesh and many residences of mentally retarded persons.

In Rajshahi, contacts with the families were established through the (CDC) Child Development Centre of (RMCH) Rajshahi Medical College Hospital. He also observed the children and obtained first hand data from these centers. As well as he visited many houses of Rajshahi city. He discussed with the parents of the mentally retarded children and obtained information from them in the printed questionnaire and his note book. The researcher was always in contact with the families through cell phones and personal visits. The respondents of this study were the parents, mainly of the mentally retarded persons. The background information about the respondents is shown in the following tables:

**Table-1: Relationship of the respondents with the mentally retarded persons**

Relation	Frequency	Percent
Mother	73	81.10
Father	17	18.90
<b>Total</b>	<b>90</b>	<b>100.00</b>

It was found that mothers were more as the respondents. As the fathers remain busy outside, so they were not always available along with their mentally retarded children as well as to the data collector. So in this study mothers (81.10%) were the majority of the respondents. This was also beneficial in this study, because most of the information could not be found other than the mothers. Mothers were related with the pregnancy, lactation and overall brought up of the mentally retarded children. The mothers also could inform the prenatal, postnatal and other developments of the children better than the fathers.

**Table-2: Education of the respondents**

Category of education	Frequency	Percent
Primary	35	38.90
Secondary	16	17.80
Intermediate	17	18.90
Graduate	12	13.30
Post graduate	10	11.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table shows that majority of the respondents were of primary education (38.90). It was mentioned earlier that the selection of cases and their parents were done purposefully. One major criterion was the knowledge and literacy level of the parents. Secondly, the seriousness to preserve medical papers of their children.

**Table-3: Profession of the respondents**

Profession	Frequency	Percent
Service holder	7	7.70
Business	5	5.60
Farmer	5	5.60
Housewife	69	76.70
Others	4	4.40
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that most of the respondents were housewives (76.7%). The profession of the respondents were not the selection criteria of the researcher. When the selection was done considering their seriousness and ability to respond, the above distribution came up when the researcher compiled the purposefully selected cases.

**Table-4: Economic status of the family**

<b>Economic status</b>	<b>Frequency</b>	<b>Percent</b>
Poor	42	46.70
Lower Middle	30	33.30
Middle	15	16.70
Upper Middle	3	3.30
Rich	00	00.00
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table shows that most of the families were poor or of lower middle class status. There are mentally retarded children in rich families. But the parents did not co-operate with the respondent to enter into the depth.

**Table-5: Residence of the respondents**

<b>Residence</b>	<b>Frequency</b>	<b>Percent</b>
Rural	40	44.40
Urban	50	55.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

Two cities i.e. Dhaka and Rajshahi and some villages of Rajshahi District were taken as study areas. 55.6% urban and 44.4% rural respondents were studied. These 90 respondents were purposively selected to represent a brief scenario.

**Table-6: Family type of the respondents**

<b>Family type</b>	<b>Frequency</b>	<b>Percent</b>
Joint family	32	35.60
Nuclear family	58	64.40
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that majority of the families were of nuclear type (64.40%). The country is now in a period of transition from joint family to nuclear family type. It has great impact on the children.

### **Basic information of the cases studied**

Ninety mentally retarded persons were studied. The following tables are showing their basic information:

**Table-7: Age of the studied cases**

<b>Age ( in years)</b>	<b>Frequency</b>	<b>Percent</b>
1-5	23	25.56
6-10	39	43.33
11-14	20	22.22
15-17	02	2.23
18-21	03	3.33
22-25	03	3.33
<b>Total</b>	<b>90</b>	<b>100.0</b>

In the above table the age distribution of the clinical subjects are shown. Though throughout the world the life span of the mentally retarded persons is increasing due to development of medical science, in this study their age was found up to 25 years of age. It is found in many studies that those whose life spans are more they mainly belong to milder group of mentally retarded persons. So they were not noticed by the people as mentally retarded and in this way they remained away from the study. The above table shows that most of the mentally retarded persons were at the age of 6-10 years.

**Table-8: Sex of the studied cases**

<b>Sex</b>	<b>Frequency</b>	<b>Percent</b>
Male	56	62.20
Female	34	37.80
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table shows majority of the mentally retarded persons were male. Among the 90 mentally retarded persons 56 were male and 34 were female. Here it was found that females were too much less than the males as subjects of this study. But this does not represent the prevalence of male female ratio of the country. Probably the ratio may be equal in Bangladesh. This finding came because many mentally retarded girls living in the rural areas were not given any care at CDCs or NGOs.

**Table-9: Body builds of the studied cases**

<b>Body build</b>	<b>Frequency</b>	<b>Percent</b>
Obese	16	17.80
Average	52	57.80
Thin	21	23.30
Very thin	1	1.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that majority of the cases were of average in body build. In many cases e.g. Pradder-Willy syndrome, Angel man syndrome, and where there is low physical work the mentally retarded persons are found to be obese. On the other hand due to poverty, less nutrition they may be thin. Here the subjects are same as it is reported elsewhere.

**Table-10: When the cases were detected as mentally retarded**

<b>When detected</b>	<b>Frequency</b>	<b>Percent</b>
At birth	21	23.30
Childhood	17	18.90
Later	52	57.80
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that most of the persons were detected as mentally retarded in delayed period after their births. Due to less consciousness of the people usually mental retardation is detected later in Bangladesh.

**Table-11: Persons who finally assessed the mentally retarded conditions**

<b>Assessed by</b>	<b>Frequency</b>	<b>Percent</b>
Psychologist	9	10.00
Physician	68	75.60
Others	13	14.40
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that the mentally retarded persons were assessed by physicians in most of the cases. To detect mental retardation measurement of intelligence quotient is required which is handled by clinical psychologist. Due to lack of psychologist usually it is done by the physicians in Bangladesh.

**Table-12: Level of mental retardation**

<b>Level of mental retardation</b>	<b>Frequency</b>	<b>Percent</b>
Mild	14	15.60
Moderate	16	17.80
Severe	30	33.30
Don't know	30	33.30
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that 33.30% of the mentally retarded persons were of severe category. Usually mild and moderate mentally retarded persons are not noticed by the people as they can live nearly normal life in rural areas. During home visits, the researcher observed that who mentioned don't know are mainly moderately retarded as most of them need help in DLA (Daily Living Activities).

**Table-13: Profession of the mentally retarded persons**

<b>Profession</b>	<b>Frequency</b>	<b>Percent</b>
Student of Special Schools	50	55.60
Don't go to school	10	11.10
Do nothing	24	26.70
Other	6	6.70
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that majority of the mentally retarded persons are special school students. In this study majority of the respondents were children, so usually they were found as students. The six cases, which were categorized as 'other' or Do nothing either loiter in the neighborhood or help their family business. Among the 24 cases who primarily mentioned 'do nothing' were also found helping in family works or are engaged in seasonal agricultural works if living in villages.



**Table-14 with whom the mentally retarded persons live**

<b>Living with</b>	<b>Frequency</b>	<b>Percent</b>
Parents	89	98.90
Close relatives	1	1.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that most of the mentally retarded persons live with their parents. There is no residential institutionalization in Bangladesh. At the same time parents are the main caregivers of the mentally retarded persons. Society and the Government are still silent in this respect. So in this study it was found that the subjects are mostly living inside their own families and with their parents.

### **Data analysis:**

All collected information and data were checked and rechecked for omission, inconsistencies and improbabilities. The portion of quantitative Data analysis was performed by Statistical Package for Social Sciences. After cleaning of data it was edited, coded and entered into the computer. Frequency tables, summary tables and appropriate graphs were prepared to show the findings. The goal of data analysis was done to meet the study objectives. The appropriate statistical tests were done to see the trends of the data. The socio-demographic and relevant variables were compared and mostly the chi-square tests were applied. The level of significance in this study was considered as 5% level or higher.

### **Methods and procedure**

The researcher mainly followed case study method in this study. Observation and free discussion methods were also used to go into the depth of this study. The researcher didn't follow any formal specific procedure; rather he tried to understand the situation. He tried his best to know how to improve the medical and psychosocial conditions.

### **Ethical issues**

Ethical issues were maintained to its highest level throughout the study. Informed consent was taken from the respondents. The objectives of this study were stated clearly to them and confidentiality was maintained accordingly.

## **Chapter - III**

### **Results**

The overall findings, based on observation, case studies, interviews, etc. are described in the next chapter. This chapter is based on some quantitative findings.

The researcher provided questionnaire to 90 respondents and the respondents gave answers which were in relation to the title and objectives of this research. The findings were classified as follows:

1. Medical care in relation to prevention of mental retardation.
2. Medical care for the diseases which were interrelated with the condition of mental retardation.
3. Medical care for those diseases which also occur among all the people.
4. Psychosocial care
  - (a) Psychological (mainly emotion)
  - (b) Education
  - (c) Earning
  - (d) Housing
  - (e) Social life
  - (f) Recreation
5. Role of various authorities and organizations
6. Evaluation of the services

#### **Medical care in relation to prevention of mental retardation**

Till now mental retardation is not curable, but to a large extent it can be prevented. It requires due awareness and to take specific measures to prevent mental retardation. Following table show how far there was awareness and measures taken in the 90 cases that were studied. The measures taken were assessed are related to the causes of mental retardation, possible genetic causes, care during pregnancy and labour, care for safe development of the fetus, care during infancy and childhood.

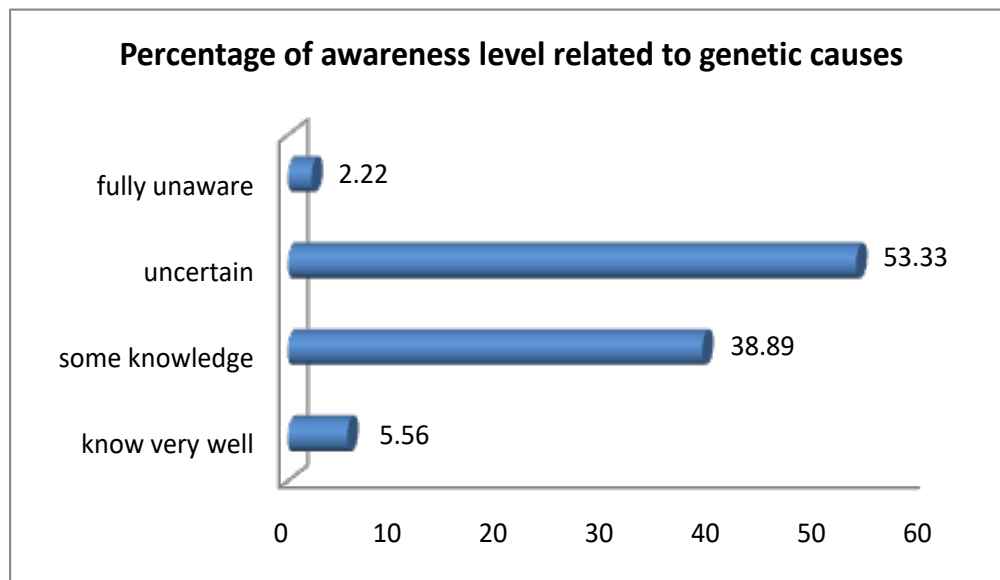
**(A) Medical care for genetic causes of mental retardation**

Among the biological causes of mental retardation genetic causes are the most important. In this study some possible genetic causes of mental retardation and measures to prevent them were assessed. The possible causes searched were presence of hereditary diseases in the families, history of previous abortion or neonatal death, maternal age and consanguinity among the parents of the mentally retarded persons. These were again studied in respect of residence (i.e., rural/urban), income and education of the families of the mentally retarded persons.

## Awareness related to genetic causes

As awareness is the basic condition which initiates to take measures to prevent the causes of mental retardation, it was first assessed among the respondents. The tables below show the state of awareness and its relation with the residence, income and education of the respondents.

### Graph Number: 1



The above graph shows that majority of the respondents were unaware that mental retardation can occur due to genetic causes. 2.22% respondents were fully unaware that i.e. they are totally ignorant or there may be stigma among them to accept the condition as it may give a negative impression about their families. Then 53.33% of the respondents were unaware whether genetic causes are responsible for mental retardation, which represents the prevailing status of ignorance, superstition and lack of scientific knowledge among them. Though throughout the world a revolution is going on regarding genetics, yet these people are not conscious about this. The educational and information system of the country are probably not working about this. Then 38.89% respondents know it to some extent and 5.56% know it very well. It indicates that scientific knowledge is limited within a few people. The interest of the people and all authorities are remarkably less to achieve a scientific status of life and wisdom till now in Bangladesh.

**Table No. 1(a)****Cross Tabs of Level of Education of Respondents and awareness level of genetic causes**

Awareness level	Number & Percentage	Level of Education of Respondents					Total
		primary	secondary	intermediate	graduates	post graduates	
know very well	Count	0	0	2	3	0	5
	%	.0%	.0%	40.0%	60.0%	.0%	100.0%
some knowledge	Count	9	5	7	5	9	35
	%	25.7%	14.3%	20.0%	14.3%	25.7%	100.0%
uncertain	Count	26	10	8	4	0	48
	%	54.2%	20.8%	16.7%	8.3%	.0%	100.0%
fully unaware	Count	0	1	0	0	1	2
	%	.0%	50.0%	.0%	.0%	50.0%	100.0%
Total	Count	35	16	17	12	10	90
	%	38.9%	17.8%	18.9%	13.3%	11.1%	100.0%

$$\chi^2 = 36.106, df = 12, P < 0.000$$

The above table shows the number and percentages found during cross tabulation of education and awareness of genetic causes.

It was found that out of 90; only 5 respondents know very well that genetic causes can be important factors of mental retardation. These 5 respondents are graduates or post graduates.

35 respondents possess some knowledge. Among them 21 respondents possess intermediate or above level of education.

48 respondents are uncertain about this factor. 36 of them have primary or secondary education.

But the researcher observed that it is not the level of education of the respondents, where there are educational institution or hospital and NGOs are working, the surrounding people are more aware of the genetic causes. The prevalence of mental retardation is relatively lesser in those areas.

**Table No. 1(b)****Cross Tabs of economic status of respondents and awareness level of genetic causes**

Awareness level	Number & Percentage	Economic status of Respondents				Total
		Poor	Lower middle	Middle	Upper middle	
know very well	Count	1	3	1	0	5
	%	20.0%	60.0%	20.0%	.0%	100.0%
some knowledge	Count	11	9	12	3	35
	%	31.4%	25.7%	34.3%	8.6%	100.0%
uncertain	Count	30	16	2	0	48
	%	62.5%	33.3%	4.2%	.0%	100.0%
fully unaware	Count	0	2	0	0	2
	%	.0%	100.0%	.0%	.0%	100.0%
Total	Count	42	30	15	3	90
	%	46.7%	33.3%	16.7%	3.3%	100.0%

$$\chi^2 = 26.458, df = 9, P < 0.002$$

The above table shows the number and percentages found during cross tabulation of economic status of the respondents and their awareness levels related to genetic causes. It was found that only 40 respondents know that genetic causes are factors. 48 respondents are uncertain and 2 respondents are fully unaware. The findings do not project that economic status is related to their awareness.

Considering his close observation and informal interactions, interviews, etc. the researcher understood that it is the mass media and propaganda that work behind the awareness.

In this study extremely rich people did not agree to continue as respondents. Most of them observed try to hide their mentally retarded children and take care of their children in the home in an isolated way.

**Table No. 1(c)****Cross Tabs of Rural Urban Residence of Respondents and awareness level of genetic causes**

	Number & Percentage	Rural Urban Residence of Respondents		Total
		Rural	Urban	
know very well	Count	2	3	5
	%	40.0%	60.0%	100.0%
some knowledge	Count	11	24	35
	%	31.4%	68.6%	100.0%
uncertain	Count	26	22	48
	%	54.2%	45.8%	100.0%
fully unaware	Count	1	1	2
	%	50.0%	50.0%	100.0%
Total	Count	40	50	90
	%	44.4%	55.6%	100.0%

$$X^2 = 4.304, df = 3, P < 0.230$$

The above table shows the number and percentages found during cross tabulation of urban rural residence status of the respondents and their awareness levels related to genetic causes. It was found that only 27 urban and 13 rural respondents knew that genetic causes are factors of mental retardation. Again 26 rural and 22 urban respondents are yet uncertain in this regard.

Considering his personal visits, interviews, observations, etc. the researcher again emphasizes that it is not the rural urban living places; rather it is the mass media and visits of the health workers who can really develop awareness.

Now a days media is extended throughout the world and rural and urban becoming the member of a single global village. So the gap between the people are gradually diminishing in respect of residence.

## Possible conditions related to genetic causes

**Table-2 whether hereditary diseases were present in the family**

In many studies it was found that those families who suffer from hereditary diseases, the possibility of giving birth of mentally retarded children are more among them. The tables below show how far it was found in this study.

**Table-2(a): Hereditary diseases in the family and residence**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Residence	Rural	12	13.30	28	31.10	40	44.40
	Urban	23	25.50	27	30.00	50	55.50
Total		33	38.80	55	61.10	90	100.00

**Table-2 (b): Presence of hereditary diseases in respect of income**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Income (N-90)	Poor	14	15.50	28	31.10	42	46.60
	Rich	21	23.30	27	30.00	48	53.30
Total		35	38.80	55	61.10	90	100.00

**Table-2 (c): Presence of hereditary diseases in respect of education**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Education (N-90)	Low educated	15	16.60	36	40.00	51	56.60
	High educated	20	22.20	19	21.10	39	43.30
Total		35	38.80	45	61.10	90	100.00

61.1% respondents stated that they had no hereditary diseases in their family. Then urban (46.67%), rich (47.92%) and highly educated (51.28%) said to have more hereditary diseases than the rural (30%), poor (33.33%) and low educated (29.41%) respondents. It may not be the exact feature. Probably hereditary diseases occur equally or more in the later groups. But the urban, rich and highly educated people are more conscious about the hereditary diseases, so it came into their notice.



### Table - 3 History of previous abortion or neonatal death

**Table - 3 (a): Previous abortion or neonatal death and residence**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Residence (N-90)	Rural	2	2.20	38	42.20	40	44.40
	Urban	7	7.70	43	47.70	50	55.50
<b>Total</b>		<b>9</b>	<b>9.90</b>	<b>81</b>	<b>89.90</b>	<b>90</b>	<b>100.00</b>

**Table - 3 (b): Previous abortion or neonatal death and income**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Income (N-90)	Poor	4	4.40	38	42.20	42	46.67
	Rich	5	5.56	43	47.78	48	53.30
<b>Total</b>		<b>9</b>	<b>9.96</b>	<b>81</b>	<b>89.98</b>	<b>90</b>	<b>100.00</b>

**Table - 3 (c): Previous abortion or neonatal death and education**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Education (N-90)	Low educated	6	6.67	45	50.00	51	56.67
	High educated	3	3.30	36	40.00	39	43.30
<b>Total</b>		<b>9</b>	<b>9.97</b>	<b>81</b>	<b>90.00</b>	<b>90</b>	<b>100.00</b>

In table 3a it is seen that neonatal death is relatively more among the urban cases, though negligible, the findings do not project that urban rural living places are important factors. Rather, the socioeconomic conditions and physiological conditions are important.

In Table 3b it is seen that higher economic group gave slightly more reports of abortion or neonatal deaths. But again it is not the economic status; rather the health care is the related factor.

In table 3c it is seen that compared to the higher educated the lower educated mothers reported more abortions or neonatal deaths.

Considering the personal visits, interviews, reviewing previous medical records, etc. the researcher understood that each case had unique and specific backgrounds. Therefore, the researcher does not like to come to any conclusion that the rural-urban living places, levels of education or income are related factors of previous history of abortion or neonatal deaths.

**Table – 4: Maternal age 35 years or more****Table - 4(a): Maternal age 35 years or in respect of residence**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Residence (N-90)	Rural	3	3.30	37	41.10	40	44.40
	Urban	1	1.10	49	54.40	50	55.56
<b>Total</b>		<b>4</b>	<b>4.40</b>	<b>86</b>	<b>95.50</b>	<b>90</b>	<b>100.00</b>

**Table - 4(b) : Maternal age 35 years or more in respect of income**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Income (N-90)	Poor	2	2.20	40	44.40	42	46.67
	Rich	2	2.20	46	51.10	48	53.30
<b>Total</b>		<b>4</b>	<b>4.40</b>	<b>86</b>	<b>95.50</b>	<b>90</b>	<b>100.00</b>

**Table - 4(c): Maternal age 35 years or more and education**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Education (N-90)	Low educated	3	3.30	48	53.30	51	56.67
	High educated	1	1.10	38	42.20	39	43.30
<b>Total</b>		<b>4</b>	<b>4.40</b>	<b>86</b>	<b>95.50</b>	<b>90</b>	<b>100.00</b>

Findings presented in the three tables are self explanatory showing the number and percentage of respondents. In table 4a it is seen that 4.4% mothers were above 35 years and 95.5% were below 35 years in age when they conceived the mentally retarded children. In table 4b it is seen that 2.2% poor and 2.2% rich mothers conceived mentally retarded children when they were aged above 35 years. In table 4c it is seen that 3.3% low educated and 1.1% high educated mothers conceived the mentally retarded babies. It appears that there are differences of percentages of cases in relation to the variables like rural urban living places and education levels of the moths. But the percentages of the cases are so negligible that it can not be concluded that the differences can be significant. But yes, from the review of literature, observations, interviews, etc. the researcher found that conception of mother aged 35 or above are hazardous in many ways.

**Table - 5 Consanguinity among the parents of the mentally retarded persons**

**Table - 5(a)**

**Consanguinity in relation to residence**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Residence (N-90)	Rural	0	00.00	40	44.40	40	44.40
	Urban	10	11.10	40	44.40	50	55.56
<b>Total</b>		<b>10</b>	<b>11.10</b>	<b>80</b>	<b>88.80</b>	<b>90</b>	<b>100.00</b>

**Table - 5(b)**

**Consanguinity in relation to income**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Income (N-90)	Poor	3	3.30	39	43.30	42	46.67
	Rich	7	7.78	41	45.56	48	53.30
<b>Total</b>		<b>10</b>	<b>11.08</b>	<b>80</b>	<b>88.86</b>	<b>90</b>	<b>100.00</b>

**Table - 5(c)**

**Consanguinity in relation to education**

Categories of respondents		Yes		No		Total	
		N	%	N	%	N	%
Education (N-90)	Low educated	6	6.67	45	50.00	51	56.67
	High educated	4	4.40	35	38.89	39	43.30
<b>Total</b>		<b>10</b>	<b>11.07</b>	<b>80</b>	<b>88.89</b>	<b>90</b>	<b>100.00</b>

Consanguinity was found in 11.1% cases. In a study (Islam et al., 1993) it was found 60% of the mentally retarded children were offspring's of consanguineous parents in Bangladesh. This study indicates that the situation has improved in course of time. It was 0% among the rural and 7.5% in the poor respondents which was too much less than their counter groups i.e. urban (20%) and rich (14.58%) respondents. In the society so called aristocracy or superiority complex may be the cause of consanguinity in these rich and urban groups. They want to keep limited the marital bond within relatives and nearby society. Education didn't influence their thinking; it was found 11.76% in low educated 10.26% in highly educated respondents, which was nearly same.

## Tables regarding measures taken to prevent hereditary causes of mental retardation

**Table- 6(a): Prevention of hereditary diseases in respect of residence**

Categories of respondents		Advice taken from							
		Specialist doctors		Alternative medicine		Nothing		Total	
		N	%	N	%	N	%	N	%
Residence (N-90)	Rural	10	11.10	3	3.30	27	30.00	40	44.40
	Urban	4	4.40	1	1.10	45	50.00	50	55.56
<b>Total</b>		<b>14</b>	<b>15.50</b>	<b>4</b>	<b>4.40</b>	<b>72</b>	<b>80.00</b>	<b>90</b>	<b>100.00</b>

**Table - 6(b): Prevention of hereditary diseases in respect of income**

Categories of respondents		Advice taken from							
		Specialist doctors		Alternative medicine		Nothing		Total	
		N	%	N	%	N	%	N	%
Income (N-90)	Poor	7	7.78	4	4.40	31	34.40	42	46.67
	Rich	7	7.78	0	0.00	41	45.56	48	53.30
<b>Total</b>		<b>14</b>	<b>15.56</b>	<b>4</b>	<b>4.40</b>	<b>72</b>	<b>89.96</b>	<b>90</b>	<b>100.00</b>

**Table - 6(c): Prevention of hereditary diseases in respect of education**

Categories of respondents		Advice taken from							
		Specialist doctors		Alternative medicine		Nothing		Total	
		N	%	N	%	N	%	N	%
Education (N-90)	Low educated	5	5.56	4	4.40	42	46.67	51	56.67
	High educated	9	10.00	0	0.00	30	33.30	39	43.30
<b>Total</b>		<b>14</b>	<b>15.56</b>	<b>4</b>	<b>4.40</b>	<b>72</b>	<b>79.97</b>	<b>90</b>	<b>100.00</b>

80% of the parents did nothing for possible hereditary diseases. 25% rural, 16.67% poor took specialist advice in comparison to 8% urban and 14.58% rich respondents. This shows that rural and poor respondents were more conscious than the urban and rich respondents regarding measure for possible hereditary problems. But highly educated took specialist advice in 23.08% cases, which was more than the low educated that was in 9.8% cases. It means that education was more important than residence and financial state to influence the parents to take specialist advice regarding hereditary problems.

## **(B) Medical care at pregnancy and labour**

Poor maternal care, perinatal birth injuries, poor neonatal care and malnutrition were among the principal factors that leads to increased prevalence of mental retardation in Bangladesh (Rabbani, 2009).

**Table - 7**  
**Vaccination taken by the mother**

<b>Vaccination taken</b>	<b>Frequency</b>	<b>Percent</b>
Yes	76	84.40
No	14	15.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

**Table - 8**  
**Regular check up done during pregnancy**

<b>Checkup done during pregnancy</b>	<b>Frequency</b>	<b>Percent</b>
Yes	70	77.80
No	20	22.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

**Table - 9**  
**Nutritious foods, vitamins and folic acid taken or not**

<b>Nutritious food, vitamins, folic acid taken</b>	<b>Frequency</b>	<b>Percent</b>
Yes	56	62.20
No	34	37.80
<b>Total</b>	<b>90</b>	<b>100.00</b>

Most of the mothers were found who took vaccination (84.4%), checked up during pregnancy was found in 77.8% cases, and took nutritious food and other supplements in 62.2% cases during pregnancy in the current study. So it can be said that mothers and their families are now aware about the importance of maternal care during pregnancy.

## Tables for mental condition of the mothers during pregnancy

**Table - 10(a): Mental condition of the mothers and residence**

Categories of respondents		Mental condition of mothers during pregnancy					
		Felt stress		Not felt stress		Total	
		N	%	N	%	N	%
Residence (N-90)	Rural	23	25.56	17	18.89	40	44.40
	Urban	19	21.10	31	34.40	50	55.56
<b>Total</b>		<b>42</b>	<b>46.66</b>	<b>48</b>	<b>53.29</b>	<b>90</b>	<b>100.00</b>

**Table - 10(b): Mental condition of the mothers and income**

Categories of respondents		Mental condition of mothers during pregnancy					
		Felt stress		Not felt stress		Total	
		N	%	N	%	N	%
Income (N-90)	Poor	22	24.40	20	22.20	42	46.67
	Rich	20	22.20	28	31.10	48	53.30
<b>Total</b>		<b>42</b>	<b>46.60</b>	<b>48</b>	<b>53.30</b>	<b>90</b>	<b>100.00</b>

**Table - 10(c): Mental condition of the mothers and education**

Categories of respondents		Mental condition of mothers during pregnancy					
		Felt stress		Not felt stress		Total	
		N	%	N	%	N	%
Education (N-90)	Low educated	24	26.67	27	30.00	51	56.67
	High educated	18	20.00	21	23.30	39	43.30
<b>Total</b>		<b>42</b>	<b>46.67</b>	<b>48</b>	<b>53.30</b>	<b>90</b>	<b>100.00</b>

46.7% mothers felt many sorts of stress during pregnancy, which may be due to overall psychosocial, educational and cultural factors of the society. Rural mothers (57.5%) felt more stress than urban mothers (38%), which may be due to ignorance of the rural people about care of the pregnant mothers. Rich mothers (41.67%) felt more stress than the poor mothers (21.43%). This may be as the rich people have more complex lives than the poor's. In respect of education both low (49.02%) and highly educated (46.15%) were nearly similar. Education usually makes people able to cope with the stress. But in this study it shows equal condition irrespective of educational state. This may be due to enormous social burden that is to face by the highly educated people. They are not getting due jobs and their demands are not fulfilling as per their desire and needs. Society also expects more from them. On the other hand less educated people bear less complex life and rather a simple life.

**Table-11****History of taking alcohol, substance of abuse, smoking, illicit drugs or drugs without prescription**

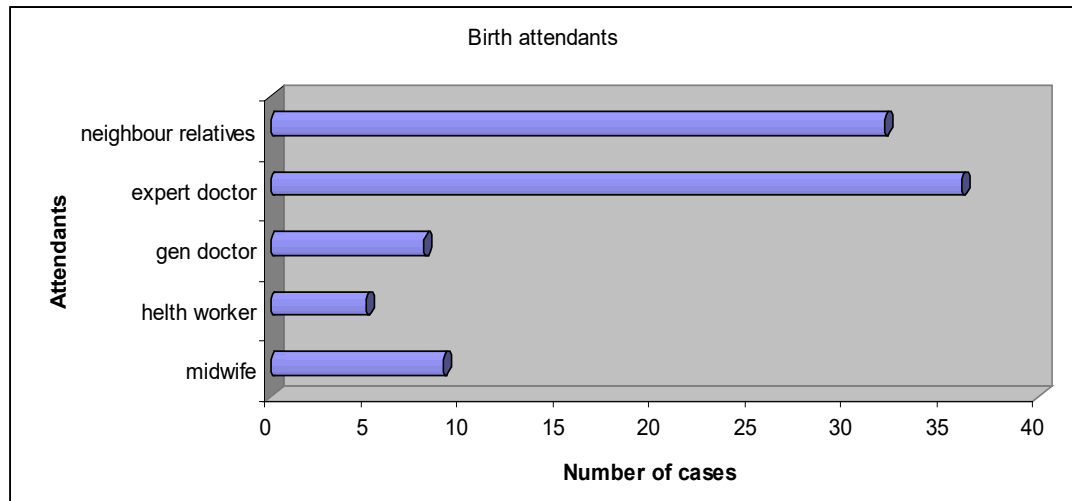
<b>History of taking</b>	<b>Frequency</b>	<b>Percent</b>
Yes	8	8.90
No	82	91.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

Most of the mothers (91.1%) took no medicine without prescription and also didn't take alcohol or substance of abuse. Previously people were unaware and usually took medicine without prescription. But this study shows that the situation has improved and the pregnant mothers are cautions to take medicine without prescription. Alcohol and substance abuse were absent, which may be due to cultural factors and strong social custom which prohibit alcoholic drinks and drugs in this country.

## Birth attendants

The following graph shows the categories of birth attendants and the number of cases studied in this research work. It was found that 36 cases were finally attended by expert doctors in the hospitals and clinics.

Graph Number: 2



Labour was conducted by expert doctors in 40% cases, 35.65% cases by relatives and neighbours and remaining 24.40% by semiskilled persons. According to WHO report (2004) it was found that 13% of the labour was conducted by doctors and trained nurses or midwives in Bangladesh. This study shows more positive findings among these respondents than it was found in WHO report.



**Table -12 (a)****Cross Tabs of Level of Education of Respondents and Categories of birth attendants**

Categories of birth attendants	Number & Percentage	Level of Education of Respondents					Total
		primary	secondary	intermediate	graduates	post graduates	
midwife	Count	8	0	0	1	0	9
	%	88.9%	.0%	.0%	11.1%	.0%	100.0%
health worker	Count	0	2	2	1	0	5
	%	.0%	40.0%	40.0%	20.0%	.0%	100.0%
gen doctor	Count	2	0	4	2	0	8
	%	25.0%	.0%	50.0%	25.0%	.0%	100.0%
expert doctor	Count	9	7	7	6	7	36
	%	25.0%	19.4%	19.4%	16.7%	19.4%	100.0%
neighbour relatives	Count	16	7	4	2	3	32
	%	50.0%	21.9%	12.5%	6.2%	9.4%	100.0%
Total	Count	35	16	17	12	10	90
	%	38.9%	17.8%	18.9%	13.3%	11.1%	100.0%

$$\chi^2 = 30.68, df = 16, P < 0.015$$

The above table shows cross tabulation of education and birth attendants. Low educated respondents took more service from the semiskilled persons, relatives and neighbors then the expert doctors. Whereas higher educated mothers took more expert services.

**Table No. 12(b)****Cross Tabs of economic status of Respondents and Categories of birth attendants**

Categories of birth attendants	Number & Percentage	Economic status of Respondents				Total
		Poor	Lower middle	Middle	Upper middle	
midwife	Count	6	2	1	0	9
	%	66.7%	22.2%	11.1%	.0%	100.0%
health worker	Count	2	2	0	1	5
	%	40.0%	40.0%	.0%	20.0%	100.0%
gen doctor	Count	2	3	3	0	8
	%	25.0%	37.5%	37.5%	.0%	100.0%
expert doctor	Count	11	13	10	2	36
	%	30.6%	36.1%	27.8%	5.6%	100.0%
neighbour relatives	Count	21	10	1	0	32
	%	65.6%	31.2%	3.1%	.0%	100.0%
Total	Count	42	30	15	3	90
	%	46.7%	33.3%	16.7%	3.3%	100.0%

$$X^2 = 22.26, df = 12, P < 0.035$$

The above table shows cross tabulation between economic status and the birth attendants. Poor people took more services from the expert doctors as they can go easily to Government hospitals of low cost services. Whereas, the middle class people hesitate or delay to take services, like the poor people, from the Government hospitals. On the other hand they had no ability to take services from the high cost private clinics.

**Table No. 12(c)****Cross Tabs of Rural Urban Residence of Respondents and Categories of birth attendants**

Categories of birth attendants	Number & Percentage	Rural Urban Residence of Respondents		Total
		Rural	Urban	
midwife	Count	1	8	9
	%	11.1%	88.9%	100.0%
health worker	Count	0	5	5
	%	.0%	100.0%	100.0%
gen doctor	Count	3	5	8
	%	37.5%	62.5%	100.0%
expert doctor	Count	14	22	36
	%	38.9%	61.1%	100.0%
neighbour relatives	Count	22	10	32
	%	68.8%	31.2%	100.0%
Total	Count	40	50	90
	%	44.4%	55.6%	100.0%

$$X^2 = 16.31, df = 4, P < 0.003$$

The table shows cross tabulation between rural and urban respondents and their birth attendants. Urban respondents took more services from the expert doctors and midwives than the rural respondents who took more services from the neighbours and relatives. The importance of delivery as a medical emergency is less understood by the rural people and it is also less available to them.

### C) Measures for Safe Development of the Fetus

**Table -13**

**Measures during pregnancy for safe development of the fetus**

Measures taken during pregnancy	Yes		No	
	N	%	N	%
Proper rest and sleep	67	74.40	23	25.56
Avoid sick persons	52	57.78	38	42.20
Felt difficulties in transport	26	28.89	64	71.10
Lift heavy objects	39	43.30	51	56.67
<b>Total</b>	<b>145</b>	<b>204.37</b>	<b>176</b>	<b>195.53</b>

Majority of the mothers (74.4%) took proper rest and sleep. 57.8% mothers avoided sick persons. 71.1% mothers didn't suffer from difficulties in transport. 56.7% mothers didn't lift heavy objects during pregnancy. These findings are positive to some extent, but not to the highest scale. It is better than the previous history of safety practices in the country, but highest possible standard is not reached, which require more efforts.

## D) Medical care during infancy and early childhood

Mental retardation can be prevented during infancy and childhood by knowing the causes and taking steps to keep children safe and healthy. These may be immunization, injury prevention, newborn screening and treating the condition as far it is possible, reducing the intake of harmful drugs, reducing exposure to lead, mercury and toxins in the environment.

**Table -14**  
**Vaccination during infancy**

Vaccination given	Frequency	Percent
Yes	82	91.10
No	8	8.90
<b>Total</b>	<b>90</b>	<b>100.00</b>

In this study it was found 91.10% children were given vaccination. According to WHO report (2004), as many as 73% of Bangladeshi children can be considered to be fully immunized. This study shows better situation than that report. So the condition of immunization has improved or it may be the specific feature of these respondents. It can be hoped that in future 100% immunization will be possible.

**Table -15**  
**Suffering from common diseases during infancy and childhood**

Common diseases (e.g. respiratory diseases, fever, diarrhea etc.)	Frequency	Percent
Yes	67	74.40
No	23	25.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

74.40% mentally retarded persons suffered from different childhood diseases. Among these diseases fever, diarrhea and respiratory diseases were more common. These findings are consistent with other findings. In Bangladesh, it was reported that 21% of children suffer from respiratory infections, 40% from fever and 8% from diarrhea (WHO report, 2004).

**Table -16**  
**Modern screening tests done to detect mental retardation**

Modern screening tests	Yes		No		Total	
	N	%	N	%	N	%
Rural	0	0.00	40	44.40	40	44.40
Urban	17	18.89	33	36.67	50	55.56
<b>Total</b>	<b>17</b>	<b>18.89</b>	<b>73</b>	<b>81.07</b>	<b>90</b>	<b>100.00</b>

Modern screening tests for mental retardation were done in 18.89% cases. None of the rural had done these tests. 34% of the urban cases have done the screening tests. Screening tests for mental retardation is just beginning in the country, so the number is too much less. Also it is not affordable by most of the people. Secondly the rural people were found mostly unaware about this. Some people go abroad for this purpose which is rare. It is related with proper awareness, socioeconomic condition as well as overall development of the country.

**Table -17**  
**Severe trauma to head during infancy and childhood**

Trauma /injury to head occurred	Frequency	Percent
Yes	37	41.10
No	53	58.90
<b>Total</b>	<b>90</b>	<b>100.00</b>

It 41.1% cases severe head injury occurred in childhood. It indicates that many of the children are brought up in risky condition in the country. Head injury usually occurs during playing or fall from the beds. Head injury can cause a wide range of cause consequences e.g. unconsciousness, confusion, drowsiness, fracture of the skull or face, facial bruising, fluid drainage from the nose, mouth or ear, severe headache, personality changes, unusual behaviour, and slurred speech, blurred vision, inability to move one or more limbs and in many cases mental retardation can occur.

**Table-18****History of taking drugs which may cause Rey's syndrome**

<b>History of taking drugs which may cause Rey's syndrome</b>	<b>Frequency</b>	<b>Percent</b>
Yes	0	0.00
No	90	100.00
<b>Total</b>	<b>90</b>	<b>100.00</b>

None gave the history of taking drugs which may cause Rey's syndrome. It means unnecessary or harmful drugs were not used, which may be due to the growing concern about the abuse of drugs.

**Table-19****Exposure to lead, mercury or toxic substances in the environment**

<b>Exposure to lead, mercury or toxic substances in the environment</b>	<b>Frequency</b>	<b>Percent</b>
Yes	1	1.10
No	89	98.90
<b>Total</b>	<b>90</b>	<b>100.00</b>

Nearly none of the cases (1.1%) gave the history of exposure to lead or toxic substances in their nearby environment. In Bangladesh, people are not duly conscious about environmental pollution. They are always violating the laws and principles regarding environmental pollution in various sectors as it are found in newspapers and Medias. But this study shows the opposite picture, which indicates that the condition is improving day by day, though it is not noticed by all. In Dhaka city use of petrol mixed with Mobil is banned and now it is using CNG in motor vehicles. Smoking and polythine bag is also banned throughout the country. Though people are violating these laws, still it reduced those and thus environmental pollution is diminishing. But above all, Bangladesh is not exposed to nuclear radiation like Japan and Russia.

## Medical Care after Detection of Mental Retardation

Diseases are found more among the people with mental retardation than the others. But they are not duly identified. Some diseases are found as a feature of the causes related with mental retardation. Other diseases occur as they occur among all the people.

**Table-20**

### Diseases Directly Related with Mental Retardation

Diseases Directly Related with Mental Retardation	Frequency	Percent
Hereditary diseases	44.40	10.00
Neurological diseases	36.67	17.80
Heart diseases	44.40	4.40
Skin diseases	36.67	1.10
Other diseases	44.40	3.30
<b>Total</b>	<b>206.54</b>	<b>36.60</b>

Some diseases are found as a part of the causes of mental retardation. In this study it was found that only a few number of the mentally retarded persons were diagnosed having diseases related with mental retardation. Among these 10% gave the history of hereditary diseases, 17.8% had neurological diseases, 4.4% had heart diseases, other diseases were reported less. In international studies heart diseases neurological diseases found to be ranged from 2.8% to 9.0%, heart diseases were found 30% to 40% (Horwitz et al., 2000). In this study neurological diseases were found more and heart diseases were found lesser. Probably in these cases neurological diseases (e.g. epilepsy and others) were diagnosed easily, whereas heart diseases were not diagnosed due to lack of access to sophisticated diagnostic tools.



**Table-21**  
**Treatment taken for the diseases related with mental retardation**

Category of treatment	Frequency	Percent
By specialist doctors	23	25.60
Alternative treatment	11	12.20
Multiple system of treatments	56	62.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

Most of the mentally retarded persons (62.2%) took multiple system of treatments i.e. modern medical treatment along with homeopathy, ayurved and miscellaneous other sorts of treatments. 25.6% took care from specialist doctors and 10% took care from alternative sources of treatment e.g. homeopath, ayurved, faith healers etc. The study indicates that the guardians of the mentally retarded persons suffer from indecision regarding medical care. The ability and availability of taking specialist services are less in the country, which is also evident from this study.

**Table-22**  
**Common diseases among the mentally retardation persons**

Category of diseases	Rural		Urban	
	N	%	N	%
Multiple common diseases (fever, diarrhea, skin diseases etc.)	32	35.56	43	47.78
Respiratory diseases	6	6.67	2	2.20
Other diseases	2	2.20	5	5.56
<b>Total</b>	<b>40</b>	<b>44.40</b>	<b>50</b>	<b>55.56</b>

Most of the cases (82.2%) suffered from multiple common diseases. Then it was respiratory diseases which occurred more (8.9%) among the category of diseases. It is consistent with the findings of other studies in Bangladesh. Kabir (2011) found 67% of children having respiratory problems among 5157 children under 5 years of age. Rural cases (15%) were more than urban cases (4%) suffering from respiratory diseases. It is due to lack of awareness, care and less availability of modern treatment in the rural areas.

## Tables for treatment taken for common diseases

**Table -23(a): Treatment taken for common diseases and residence**

Categories of respondents		Category of treatment							
		Specialist doctors		Alternative treatment		Multiple system of treatments		Total	
		N	%	N	%	N	%	N	%
Residence (N-90)	Rural	3	3.30	6	6.67	31	34.40	40	44.40
	Urban	21	23.30	6	6.67	23	25.56	50	55.56
<b>Total</b>		<b>24</b>	<b>26.60</b>	<b>12</b>	<b>13.34</b>	<b>54</b>	<b>59.96</b>	<b>90</b>	<b>100.00</b>

**Table -23(b)**

**Treatment taken for taken common diseases and income**

Categories of respondents		Category of treatment							
		Specialist doctors		Alternative treatment		Multiple system of treatments		Total	
		N	%	N	%	N	%	N	%
Income (N-90)	Poor	5	5.56	8	8.89	29	32.20	42	46.67
	Rich	19	21.10	4	4.40	25	27.78	48	53.30
<b>Total</b>		<b>24</b>	<b>26.66</b>	<b>12</b>	<b>13.29</b>	<b>54</b>	<b>59.98</b>	<b>90</b>	<b>100.00</b>

**Table -23(c)**

**Treatment taken for taken common diseases and education**

Categories of respondents		Category of treatment							
		Specialist doctors		Alternative treatment		Multiple system of treatments		Total	
		N	%	N	%	N	%	N	%
Education (N-90)	Low educated	11	12.20	9	10.00	31	34.40	51	56.67
	High educated	13	14.40	3	3.30	23	25.56	39	43.30
<b>Total</b>		<b>24</b>	<b>26.60</b>	<b>12</b>	<b>13.30</b>	<b>54</b>	<b>59.96</b>	<b>90</b>	<b>100.00</b>

Rural (7.5%), poor (11.9%), and low educated (21.5%) took less specialist treatment than their counter group i.e. urban (42%), rich (39.58%) and highly educated (33.33%). These findings are consistent with our socio cultural background. Usually urban, rich and more educated people are more conscious and take more specialist treatment than the rural, poor and low educated people.

**Table -24**  
**Mothers influenced by whom to choose the treatment**

<b>Influenced by</b>	<b>Frequency</b>	<b>Percent</b>
Husband	34	37.80
Parents	19	21.10
Parents in law	2	2.20
Other than family members	35	38.90
<b>Total</b>	<b>90</b>	<b>100.00</b>

In the table above it is seen that in 37.80% cases the husbands, 21.10% cases the parents, 2.20% cases the parent-in-laws and in 38.90% outsiders influenced the mothers to choose the treatment categories.

## Mental diseases among the mentally retarded persons

**Table-25: Mental diseases found among the mentally retarded persons**

Name of the diseases	Frequency	Percent
Mental diseases (e.g. Schizophrenia, mood disorders, etc.)	68	75.60
Development of disorders	20	22.20
Behavioural problems	2	2.20
<b>Total</b>	<b>22</b>	<b>100.00</b>

Mental diseases also occur more in the mentally retarded persons than the rest of the population. But it is also not properly diagnosed. In this study majority (75.6%) of the cases suffered from various psychiatric problems (e.g. developmental disorders, schizophrenia, mood disorders, behavioural problems etc.) In many national and international studies it was found that mental diseases occur 3 to 4 times in the mentally retarded persons than the other people (Gelder et al., 2006). In a study MZR Khan (unpublished dissertation, 2010) stated that 47.9% of the mentally retarded children were suffering from mental diseases in a sample of 48 mentally retarded children in Dhaka, Bangladesh. Whereas, in a national survey it was found to be 16.05% among the population of Bangladesh (WHO, 2005).

**Table-26**

### Treatment taken by whom for mental diseases

Treatment taken by	Frequency	Percent
Psychiatrists	28	31.10
Non-psychiatrists	10	11.10
Alternative treatments (e.g. Homeopath, Ayurved, faith healers etc.)	2	2.20
More than one category of treatment (i.e., modern treatment along with alternative and others)	50	55.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

Majority of the mentally retarded persons were treated by non-psychiatrists for their psychiatric problems. In Bangladesh availability of psychiatrists is too much less and the people are also not aware about psychiatric diseases and its treatment.

## B. Psychosocial care of the mentally retarded persons in Bangladesh

Psychological/ Emotional and relevant problems related with the society

**Table-27: Psychological/Emotional problems related within the society**

Psychological/Emotional and relevant problems	Frequency	Percent
Multiple problems (e.g. neglected, avoided, misbehaved)	53	58.90
Only neglected	26	28.90
Only Avoided	11	12.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

In this study majority (58.9%) of the cases were found to have multiple social problems e.g. they were neglected, avoided and misbehaved. Only neglected in 28.9% cases, avoided in 11.1% cases. It was nearly same in various categories of respondents irrespective of rural, urban, financial or educational status.

**Table-28**  
**Problems of living with the society**

Problems of living	Frequency	Percent
Felt difficulties in living	34	37.80
Felt helpless	29	32.20
Inferiority complex	4	4.40
Didn't feel difficulties	23	25.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

The majority of the respondents suggested coordinated initiatives of the Government, NGOs, social organizations, educational institutes and the society to overcome the problems.

Though majority of the mentally retarded persons are suffering from social problems, but the situation is improving than the previous time, when they were totally avoided by the society and were bound to live inhuman lives. There is now flow of progress due to continuous efforts of WHO, UNICEF, many national-international organizations and the Government (Zaman, 1990)

**Table-29**  
**Measures to solve the problems with the society**

<b>Measures to solve the problems</b>	<b>Frequency</b>	<b>Percent</b>
Media awareness	6	6.70
Through educational curriculum	7	7.80
NGO and social workers	27	30.00
Coordination of all the above measures	36	40.00
Other proposals	14	15.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that the major portion of the respondents proposed for coordinated measures to solve the problems of living of the mentally retarded persons in the society. The details of co ordinate measures are explained in the following chapter.

## Education

**Table-30**

**Educational proposals for the mentally retarded persons**

<b>Proposals regarding education</b>	<b>Frequency</b>	<b>Percent</b>
General education	3	3.30
Special education	32	35.60
Coordinated/combined education	44	48.90
Other proposals	11	12.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

Majority (48.9%) of the respondents suggested for coordinated (inclusive) and combined education, which is the modern conception also. But many (35.6) also desired segregated special education.

The modern ideas for education of the mentally retarded persons are not well disseminated in the country. Inclusive education and its positive effects are not well-known to the people. Still the people are in favour of the modern ideas from their common senses.

## Earning

**Table-31**

**Proposals for earning of the mentally retarded persons**

<b>Proposals regarding earning</b>	<b>Frequency</b>	<b>Percent</b>
Integrated job	19	21.10
Special job	60	66.70
Other proposals	11	12.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

The table above shows that more than sixty percent of the respondents proposed special job for the mentally retarded persons.

66.7 % respondents suggest for special jobs for the mentally retarded persons. But the modern concept is 'supported employment' along with other people, which was desired by 21.1 respondents. So it can be said that the respondents are not familiar with the modern idea of earning for the mentally retarded persons duly.



## Housing

**Table-32**

**Proposals regarding housing for the mentally retarded persons**

<b>Proposals regarding housing</b>	<b>Frequency</b>	<b>Percent</b>
Family would arrange	28	31.10
Government would arrange	26	28.90
Community would arrange	34	37.80
Other proposals	2	2.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

Majority (37.8%) of the respondents seek initiatives from the community for housing of the mentally retarded persons. Then many (31.1 %) respondents thought that family will arrange the housing. 28.9% respondents thought Government will make houses for the mentally retarded persons. But experiences say that it should be an integrated effort. Family, community, Government and non-Government organizations should arrange houses for the mentally retarded persons coordinating each other.

## Social life

**Table-33**

**Proposals regarding social life of the mentally retarded persons**

<b>Proposals regarding social life</b>	<b>Frequency</b>	<b>Percent</b>
Living normally with the society	16	17.80
Segregated in institution	1	1.10
Living in the society with special care	67	74.40
Other proposals	6	6.60
<b>Total</b>	<b>90</b>	<b>100.00</b>

74.4 % respondents were in opinion of integrated social life. Once a time there were no care for the mentally retarded persons, then came the era of institutions, which was abandoned later on. Thereafter the idea of normalization evolved. Throughout the world now it is upgrading. The respondents of this study though do not know much about the trials and errors done in Europe, gave opinion what the Europe is doing now a days.

## Recreation

**Table-34**

**Proposals related with recreation of the mentally retarded persons**

<b>Proposals regarding recreation</b>	<b>Frequency</b>	<b>Percent</b>
Special arrangement for recreation	18	20.00
Normal social arrangement of recreation	12	13.30
Integrated arrangement of recreation (i.e., normal social arrangement along with special items for the mentally retarded persons)	59	65.60
Other proposals	1	1.10
<b>Total</b>	<b>90</b>	<b>100.00</b>

65.6% respondents belief that there should be integrated arrangement for recreation for the mentally retarded persons. Now there are national and international arrangements for the recreation of the mentally retarded persons, but they are limited and not duly coordinated and integrated in the society.

## **Role of various organizations and government for medical and psychosocial care of the mentally retarded persons**

**Table-35**

**Role of various authorities regarding medical and psychosocial care for the mentally retarded persons**

<b>Role of various authorities</b>	<b>Frequency</b>	<b>Percent</b>
Families, relatives and neighbours	41	45.60
NGOs and social workers	29	32.20
Government	20	22.20
<b>Total</b>	<b>90</b>	<b>100.00</b>

In 45.6% of cases the services came from the families, relatives and neighbours, 32.2% cases get services from the NGOs and 22.2% get Government services as it is found in this study.

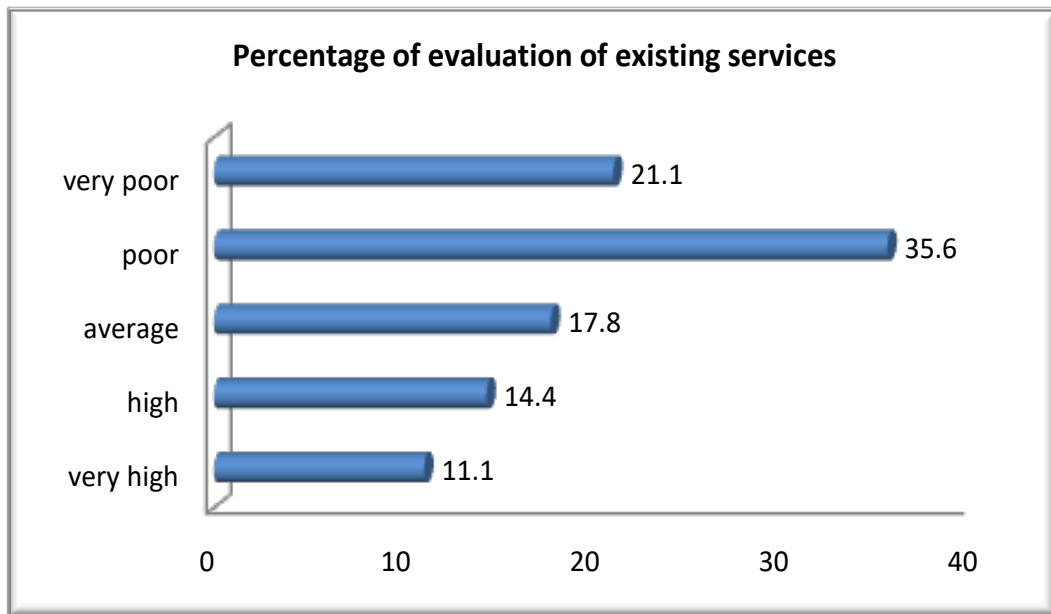
The respondents expected that the services should be upgraded both in qualities and quantities.

The researcher observed that majority of the respondents don't know about mental retardation and its causes and care. Scientific knowledge is not well circulated and most of the families feel helpless in this regard. There are lacking in service providers and their abilities are also too much less.

## Evaluation of the services

The table and graph show that majority of the respondents evaluated the services as poor.

### Graph no.3



Majority of the respondents (35.6%) evaluated the services as poor, 21% as very poor, 17.8% called it of high quality and 14.4% mentioned it nearly high. These differences may be due to socio-demographic variation of the respondents.

**Table no 36(a)****Cross Tabs of Level of Education of Respondents and evaluation of existing services**

Evaluation level	Number & Percentage	Level of Education of Respondents					Total
		primary	secondary	intermediate	graduates	post graduates	
very high	Count	4	1	3	1	1	10
	%	40.0%	10.0%	30.0%	10.0%	10.0%	100.0%
high	Count	2	5	4	2	0	13
	%	15.4%	38.5%	30.8%	15.4%	.0%	100.0%
average	Count	6	4	4	1	1	16
	%	37.5%	25.0%	25.0%	6.3%	6.3%	100.0%
poor	Count	17	2	4	4	5	32
	%	53.1%	6.3%	12.5%	12.5%	15.6%	100.0%
very poor	Count	6	4	2	4	3	19
	%	31.6%	21.1%	10.5%	21.1%	15.8%	100.0%
Total	Count	35	16	17	12	10	90
	%	38.9%	17.8%	18.9%	13.3%	11.1%	100.0%

$$X^2 = 17.917, df = 16, P < 0.329$$

The above table shows no cross tabulation of educational levels and evaluation of the services for the mentally retarded persons in Bangladesh. Majority of the respondents of all educational level considered the services as poor. It indicates that the picture of services is equally understood by nearly all the respondents. Difference in educational status was not a factor to understand the situation and it couldn't mask their perception.

**Table No. 36(b)****Cross Tabs of economic status of respondents and evaluation of existing services**

Evaluation level	Number & Percentage	Economic status of Respondents				Total
		Poor	Lower middle	Middle	Upper middle	
very high	Count	3	4	2	1	10
	%	30.0%	40.0%	20.0%	10.0%	100.0%
high	Count	3	6	4	0	13
	%	23.1%	46.2%	30.8%	.0%	100.0%
average	Count	10	2	4	0	16
	%	62.5%	12.5%	25.0%	.0%	100.0%
poor	Count	17	11	2	2	32
	%	53.1%	34.4%	6.3%	6.3%	100.0%
very poor	Count	9	7	3	0	19
	%	47.4%	36.8%	15.8%	.0%	100.0%
Total	Count	42	30	15	3	90
	%	46.7%	33.3%	16.7%	3.3%	100.0%

$$\chi^2 = 14.358, df = 12, P < 0.278$$

The above table shows cross tabulation of economic status of the respondents and how they evaluated the existing services for the mentally retarded persons in Bangladesh. Most of the Poor and middle class respondents evaluated the services as a poor one. Awareness of the services for the mentally retarded persons is equally less throughout the country both among the people and the authorities. So the situation is felt equally as poor among the people of all status.

During case studies, the researcher found that many of the mentally retarded children and adults receive some monthly financial assistance from the government through their respective union councils. Almost all of their parents evaluated the services as poor or very poor. On the other hand the researcher personally observed some cases who are economically poor, do not get any financial assistance, evaluated the services as very good. Close observation revealed that the children of these parents are of very low age and they were handled well at the CDCs of the government hospitals.

**Table No. 36(c)****Cross Tabs of Rural Urban Residence of Respondents and evaluation of existing services**

Evaluation level	Number & Percentage	Rural Urban Residence of Respondents		Total
		Rural	Urban	
very high	Count	3	7	10
	%	30.0%	70.0%	100.0%
high	Count	3	10	13
	%	23.1%	76.9%	100.0%
average	Count	8	8	16
	%	50.0%	50.0%	100.0%
poor	Count	17	15	32
	%	53.1%	46.9%	100.0%
very poor	Count	9	10	19
	%	47.4%	52.6%	100.0%
Total	Count	40	50	90
	%	44.4%	55.6%	100.0%

$$X^2 = 4.491, df = 4, P < 0.344$$

The table shows cross tabulation of rural, urban residence of the respondents to evaluate the services for the mentally retarded persons in Bangladesh. This is as the services are more or less poor throughout the country, whether it is found in urban or rural areas. It is not hidden to any one and it is easily perceivable.



## **Chapter- IV**

### **Discussion**

#### **A. Medical Care of the Mentally Retarded Persons in Bangladesh**

##### **1. Background of Medical Care of the Mentally Retarded Persons**

###### **1.1. International Perspective:**

After the World War II, UNICEF was created in 1946, initially for the benefit of children and youth who were victims of aggression in the war. Among them a large number of children and youth were found possess different disabilities. Then UNICEF pioneered and continued its activities in this field. In order to create awareness regarding the issue, the year 1981 was declared as the International Year of Disabled Persons. In 1982, the child survival and development initiative was launched with increased emphasis on universal child immunization, primary health care, safe water and sanitation, training others and community health workers. Many programs have also been introduced towards prevention and early identification of impairment and disability, both physical and mental. The role of malnutrition was detected and till now the effort to combat the deficiency is going on throughout the world. In 1990, Presidents and Prime Ministers of 71 countries joined together at the World Summit for the children and made a solemn pledge to radically reduce child death and disability from preventable diseases and malnutrition by the year 2000. Time has witnessed the fulfillment of their solemn pledge as millions of lives are saved and prevented large number of disabilities (Khan, 1996).

The above picture is optimistic to some extent and there has been marked development in medical science. Yet the access to the modern medical care is poorer for the mentally retarded persons. The persons with mental retardation have a wide range of health problems. In comparison with general population there is a higher prevalence rate of both mental disorders and (untreated) physical disorders and disabilities. The quality of primary health care for people with mental retardation seems inadequate and most of the professionals are not familiar with their needs. So the mentally retarded people along with a wide range of health problems, experience disparities in health care, shorter life span and a lack in overall health services than the rest of the population (Horwitz et al., 2000; Groningen, 2006).

## 1.2. Bangladesh Perspective:

Bangladesh government has incorporated appropriate provision for prevention of avoidable disablement in the National Health Policy (Ferdous, 2009). In the Disability Welfare Act 2001, one of its ten schedules is: "Health Care Services for the Persons with disability." It mentions:

1. To introduce Health Care Services for the persons with disability at Government and Non-government initiatives.
2. To ensure adequate supply of medical utilities for treatment of the PWDs and arrange training for the physicians/medicos attending the PWDs.
3. To supply nutrients for the persons with disabilities.
4. To include subjects/topics related to treatment of PWDs while arranging the said training for the medicos (Web-zine of international disability news and views, 2001).

At present the following activities are conducted at different levels for improving the health situation of the children with disabilities in Bangladesh:

1. The Extended Program of Immunization (EPI) of Bangladesh Government has helped to Decrease the infant mortality rate (IMR) Dropped under five mortality rate (U5MR)
2. Country wide Mass Awareness Program to prevent disability by increasing community participation.
3. Care of pregnant mothers through traditional birth attendants.
4. Bangladesh Integrated Nutrition Project (BINP) made impact to reduce malnutrition among children and women.
5. Increasing awareness about nutrition, breast feeding, food habit, home gardening and use of iodized salt.
6. Declining malnutrition and low birth weight and adaptation of family planning practices among eligible couples.
7. For detection and intervention by pediatrician, psychologist and therapist it is decided to establish Child Development Center in 14 medical college hospitals. At present Child Development Centers are available in 10 medical college hospitals in Bangladesh.
8. Initiating program for the primary and secondary prevention on the occurrence of the causes of disability (Ferdous, 2009).

Along with the government initiatives many NGOs also providing medical cares to the mentally retarded persons. Some of them are Society for the Welfare of the Intellectually Disabled (SWID) Bangladesh, Bangladesh Protibondhi Foundation (BPF), Rehabilitation Institute and Hospital for the Disabled (RIHD), Tori Foundation, GBSS (Gram Bikash Shohaok Sangestha), SIVUS Group and many other organizations. Many professionals e.g. doctors, psychologists, social workers, leaders and people are providing medical care directly or indirectly (Ferdous, 2009).

The situation is improving day by day but still it demands more development and extension of the services to encounter the problems.

## **2. Findings of the current study**

### **Medical Care in Relation to Prevention of Mental Retardation**

Primary prevention refers to a set of approaches that reduce or eliminate the risk of mental retardation in the community. Among these measures upgrading the health situation of the community as a whole can prevent many of the cases. Knowledge of the causes of mental retardation can help to reduce cases at least 25% by practicing primary prevention (Girimaj et al, 2001).

There are now advanced methods which are technology intensive and generally more expensive than primary preventive measures. Recently there have been rapid advances in the field of genetics. A new set of techniques for the detection of genetic and other disorders called molecular genetics has evolved in the last decade, which will be applicable for wider use in future (Girimaj et al, 2001).

Now WHO has developed an important approach for prevention at many levels. The levels include early intervention or preventive measures, health promotion, specific protection, early detection and intervention, disability limitation. The table below shows an overview of these levels.

**Table 1. Levels of prevention of mental retardation**

<b>Level</b>	<b>Approach</b>	<b>Intervention</b>	
Primary prevention (preventing the occurrence retardation)	Health promotion	Health education, especially for adolescent girls	
		Improvement of nutritional status in community through optimum health care facilities	
			Improvements in pre, peri and postnatal care
		Specific protection	Universal iodization of salt
			Rubella immunization for women before pregnancy
			Folic acid administration in early pregnancy
			Genetic Counseling
			Prenatal screening for congenital malformation and genetic disorders
			Detection and care for high-risk pregnancies
			Prevention of damage because of Rh incompatibility
		Universal immunization for children	
Secondary prevention(halting disease progression)	Early diagnosis and treatment	Neonatal screening for treatable disorders	
		Intervention with " at risk" babies	
		Early detection and intervention of developmental delay	
Tertiary prevention (preventing complications and maximization of functions)	Disability limitation and rehabilitation	Stimulation, training and education and vocational opportunities	
		Mainstreaming/integration	
		Support for families	
		Parental self-help groups	

Source: Girimaj et al,2001.

### **a) Medical Care for Genetic Causes of Mental Retardation**

The completion of the Human Genome Project (2002) and due to extensive public awareness of Genetic Science, it requires to integrate Genetic Health Care Approach to Primary Health Care level (Dave et al., 2005). Genetic screening program is just beginning in Bangladesh, and no epidemiological data is available. At present in depth scientific study is not possible in this field due to lack of modern scientific facilities. Some clinical observations, histories of the mentally retarded persons and their families can be taken in extensive field level only.

There are numerous genetic causes of mental retardation, among which the most frequent are Down syndrome, fragile x-syndrome, phenylketonuria (PKU), Prader-Willi syndrome, Cats Cry syndrome, Rett's disease, neurofibromatosis etc. These are found to occur in many cases where there are increased maternal age, consanguinity, hereditary disease, and previous child having congenital fault or mental retardation, history of previous abortion or neonatal death.

#### **Awareness about genetic causes of mental retardation**

Regarding awareness about genetic causes of mental retardation it was found in this study that

- (I) Majority of the respondents were unaware about the issue.
- (II) Awareness varies in relation according to residence, economic and educational status of the respondents.

The majority of the respondents were unaware that mental retardation can occur due to genetic causes, which is related with prevailing ignorance, superstitions and lack of scientific knowledge among them. Though throughout the world a revolution is going on regarding genetics, yet these people are not conscious about this. The educational and information system of the country are probably not doing sufficient work in this regard. Here it should be mentioned that as due laboratory facilities are not affordable to detect mental retardation, then mass awareness and education is must to prevent genetic causes of mental retardation (Banerjee et al.,1996).

The rich, urban and highly educated people are relatively more aware than the poor, rural and low educated respondents about genetic causes of mental retardation.

Ferdous (2009), mentioned the risk factors for mental retardation are poverty, malnutrition, maternal illiteracy in her report on intellectual disability in Bangladesh. So the facilities for life in various respects e.g. financial, education, healthcare etc. should be tried to be upgraded and equalized to all the people.

### **Hereditary diseases in the families of mentally retarded persons**

According to the statement of the respondents 38.9% of the families of mentally retarded persons had past family history of hereditary diseases in their families. In a population based study of Hou et al. (1998), It was found 15% of the families in a large population had a positive history of mental retardation. But in a study of Vashist and Yadav (2011), among the mentally retarded persons only 4.4% had family history of mental retardation. But they only mentioned mental retardation in the families and not other relevant hereditary diseases in the families. In this study relevant other diseases were also searched in the families. Because In many studies it is indicated that families having hereditary diseases may give birth to mentally retarded children. This study shows the possibility of this relationship.

In this study it was found that urban, rich and highly educated families possess more hereditary diseases in their families. This difference may be due to more medical facilities which is easily available by the urban, rich and highly educated families than the poor, rural and low educated families. The latter group has less access to the medical facilities and they are less conscious also. So the hereditary diseases were more diagnosed among the urban, rich and highly educated families. If the medical facilities were found to be same, then probably the picture might be different.

### **Abortion or neonatal death among the mothers of the mentally retarded persons**

Maternal history of abortion or neonatal morbidity and mortality was found to be related with giving birth to mentally retarded children (Durkin et al., 2000). In this study 10% of the mothers were found who mentioned previous history of abortion or neonatal death. In a study by Ahmed et al. (1996), it was found 6% spontaneous abortion recorded for 1,087 women, of which 15% had repeated abortion. It was done at Sirajganj among the general population, not only among the mothers of the mentally retarded persons. So comparing to that study it can be said that the current study among the mothers of the

mentally retarded persons shows the possibility of relationship between previous history of abortion and giving birth to mentally retarded children. In the cases of abortion the genetic defect is the cause, which was found in many studies (Kim et al., 2010).

In this study abortion or neonatal death was found more among the urban (14%) and rich (10.47%) than the rural (5%) and poor (9.52%) mothers. But it was more in the low educated (11.86%) than the highly educated (7.69%) respondents. Usually rich and urban people marry and take kids at a later age than the poor and rural people, which may be the cause of more abortion or neonatal death among the rich and urban mothers. Whereas education influenced positively because it made the highly educated more conscious about maternal care.

### **Maternal age of the mentally retarded persons**

Increased maternal age, usually above 35 years is found to be related with mental retardation, especially Down's syndrome. It was found that 10% of the mothers of the mentally retarded persons, who were above 35 years of age, had children with Down's syndrome (Sadock and Sadock, 2007). In the current study only 4.4% mothers were above the age of 35 years. In China, significant effect of age of elderly mothers as the risk factor for mental retardation was not found. In a Jordanian study (Nafi and Shaheen, 2013.) it was reported 90.7% participant mothers of mentally retarded children were under 35 years of age. This study finds 95.6% of the mothers of the mentally retarded persons were below 35 years of age.

In this study rural (7.5%) and less educated (5.88%) respondents were found having more maternal age (above 35 years) than the urban (2%) and highly educated (2.56%) respondents. The poor (4.76%) and rich (4.17%) mothers were nearly same in this regard. It indicates that economic status was less important than residential and educational status to influence the parents to take kids after 35 years of age. Some concerned researchers mentioned that mothers of less education gave birth to more mentally retarded children than the highly educated mothers. Executive Director of Bangladesh Protibondhi Foundation, Mrs. Shamim Ferdous commented that where there is hospital or educational institute, mental retardation is found to be less at those places. Urban people are more related with these facilities and they are more conscious about advanced maternal age and its effects on the offspring's.



### **Consanguinity among the parents of the mentally retarded persons**

Consanguinity was found in 11.1% cases. In a study (Islam et al., 1993), it was found 60% mentally retarded were offspring of consanguineous parents in Bangladesh. In another study MZR Khan (2009), it was found 25.7% consanguinity among the parents of the mentally retarded persons. Epidemiological study of mental retardation in Pakistan could not find any association between consanguinity and the prevalence of mental retardation.

In an Indian study (Vashist and Yadav, 2011), it was found 3.2% consanguinity among the parents of 500 mentally retarded persons. The parents were cytogenetically normal and had no history of mental retardation. The authors commented that no association between mental retardation and consanguinity was established. The current study shows that lesser percent of mentally retarded persons (11.1%) had consanguineous parents than the previous studies in Bangladesh as it is mentioned above. However, this study can't conclude that the mental retardation is due to consanguinity among the subjects of this study.

In this study consanguinity was found more among the urban (20%) and rich (14.58%) respondents than the rural (0%) and poor (7.5%) respondents. But it was nearly same in respect of education i.e., 10.26% in highly educated and 11.76% in low educated respondents. Probably the cause may be such that the rich and urban people want to keep the relationship limited within their nearby society. Besides this, it should be mentioned that previously marriage within relatives was encouraged in Bangladesh. It was thought that this type of marriage would keep the bond deep among the relatives and the society. Education is not yet influenced to change their view as it is seemed from this study. Modern science proposes that distant marriage will strengthen the human race physically, mentally and culturally.

## **Measures taken for genetic diseases**

80% of the parents did nothing for possible hereditary diseases. 25% rural, 16.67% poor took specialist advice in comparison to 8% urban and 14.58% rich respondents. This shows that rural and poor respondents were more conscious than the urban and rich respondents regarding measure for possible hereditary problems. But educated families took specialist advice in 23.08% cases, which was more than the low educated in 9.8% cases. It means that education is more important than residence and financial state to influence the parents to take specialist advice regarding hereditary problems.

## **b) Medical Care in Relation to Pregnancy and Labor**

Poor maternal care, perinatal birth injuries, poor neonatal care and malnutrition were among the principal factors that leads to increased prevalence of mental retardation in Bangladesh (Rabbani, 2009).

Public service providing maternal care includes ante-natal care, intra-natal care, post-natal care and family planning. Safe mother hood is relatively low in Bangladesh. Utilization of institutional delivery facilities is far below the recommended 'minimum acceptance level' (Banglapedia, 2012). Only 5 percent expected 0.5 million obstetric complications are attended by medical facilities. 27.5 percent of the pregnant women receive some ante-natal care, institutional delivery in only 3.5 percent, less than 10 percent birth are assisted by trained medical personnel (Banglapedia, 2012).

## **Tetanus Toxoid Vaccination during Pregnancy**

In this study most of the mothers were found obtained tetanus toxoid vaccine (84.4%). Among them 77.5% were rural mothers and 90% were urban mothers. In a report by Rahman et al., (2003), it was stated 75% of the mothers received tetanus toxoid vaccine in 1992-96 and in 1995-99 it was increased to 81%; and it was also less in rural areas. So the findings in this study projects better level than the previous reports. It is due to constant effort of the Government and other organization and increased awareness among the people. 77.5% rural mothers and 90% urban mothers took vaccine. It is consistent with other findings (NIPORT, 2001). Sometimes vaccines are less obtained from a health facility or from a provider suggesting a need to address supply side. Then 76.19% poor mother al 91.76% rich mothers took vaccine, which indicates economy is important to determine maternal

health and it's up gradation. 76.47% low educated and 94.87% highly educated mothers took vaccine. It proves education helps to become aware regarding maternal care.

### **Check up during pregnancy**

In this study 77.8% mothers were checked up by care providers during pregnancy. In 2004, in the working papers, WHO mentioned that only one third of women reported receiving antenatal care from a medically trained person in 2000, and 56% pregnant women surveyed received at least one ante-natal care from any provider in 2001. It was stated that the target of Bangladesh Government was to achieve 50% skilled attendance at delivery by 2010. So this study shows better findings in respect of that goal and previous findings. In this study rural (67.5%), poor (69.05%) and less educated (68.63%) mothers took less ante-natal care than the urban (86%), rich (85.42%) and highly educated (89.74%) mothers. It is consistent with other findings. It has been found that older, poor, rural and less educated women are less likely to seek ante-natal care in Bangladesh (Rahman et al., 2003). It is also reported that ante-natal visits from the care providers are increasing, in 1999-2000, it was 16% and it increased to 27% in 2004. But the urban-rural difference in ante-natal care was more in that report which was 71% vs. 43% respectively.

### **Mental condition of the mothers during pregnancy**

46.7% mothers felt many sorts of stress during pregnancy, which may be due to overall psychosocial, educational and cultural factors of the society. Rural mothers (57.5%) felt more stress than urban mothers (38%), which may be due to ignorance of the rural people about care of the pregnant mothers. Rich mothers (41.67%) felt more stress than the poor mothers (21.43%). This may be as the rich people have more complex lives than the poor's. In respect of education both low (49.02%) and highly educated (46.15%) are nearly similar. Education usually makes people able to cope with the stress. But in this study it shows equal condition irrespective of educational levels. This may be due to enormous social burden that is to face by the highly educated people. They are not getting due jobs and their demands are not fulfilling as per their desire and needs. Society also expects more from them. On the other hand less educated people bear less complex and simple life.

## **Drugs Taken Without Prescription, Alcohol and Substance Abuse**

Most of the mothers (91.1%) took no medicine without prescription and also didn't take alcohol or substance of abuse. Previously people were unaware and usually took medicine without prescription. But this study shows that the situation has improved and the pregnant mothers are cautions to take medicine without prescription. Alcohol and substance abuse were found absent, which may be due to cultural factors and strong social custom of the country.

## **Maternal Nutrition during Pregnancy**

In this study 62.2% mother took nutritious food, vitamin and folic acid during pregnancy. 50% rural, 50% poor and 54.90% low educated mothers compared to 72% urban, 72.92% rich and 71.79% highly educated mothers took nutritious food, vitamin and folic acid during pregnancy. In a study of three districts of Bangladesh it was found 52% of the study women took iron tables during pregnancy. So this study shows an improvement in this regard. In a review by Rahman et al., (2003), he mentioned 45% women in Bangladesh suffer from chronic energy deficiency; low birth weight incidence in 45% and 50% pregnant women are anaemic. They also mentioned over 43% women in Bangladesh are iodine deficient and more than 2.7% are night blind during pregnancy. Due to these deficiencies there is growth retardation, low birth weight babies, premature delivery and many others difficulties (Rahman et al., 2003). In this study urban, rich and highly educated mothers took more nutrition, vitamin and folic acid as they are more aware in this regard and it is affordable by them. So awareness and ability is essential to upgrade the situation.

## **Delivery Conducted by**

In Bangladesh, safe motherhood programme has tried to be promoted on an emergency basis, especially deliveries under supervision of qualified medical professionals to reduce infection and complications which lead to death or serious illness of the mothers and neonates. (Safe motherhood, 2001). In this study 40% of labour was conducted by expert doctors, 35.6% by relatives and neighbours and remaining were conducted by semiskilled persons (24.4%). Urban (44%), rich (52%) and highly educated (51.28%) mothers were more receiving expert doctors services than rural (35%), poor (26.19%) and low educated (31.37%) mothers. In a report (NIPORT et al., 2001), it was mentioned that 92% of deliveries were conducted at home, often under

unsafe and unhygienic condition. Delivery was conducted by doctors in 7.1% cases, 5% by nurses, midwives or Family Welfare Visitors. In that report it was 33% professional attendance in urban areas, than 8% in rural areas (NIPORT et al., 2001). So this study projects a better situation in relation to birth attendants.

### **c) Measures for Safe Development of the Fetus**

Proper measures should be taken during pregnancy for the mothers which prevent harm to the mothers and fetus; and ensure safe development of the fetus. In this regard pregnant mother should take due rest, a lot of sleep, take nutritious food, avoid sick persons, precaution in transport, don't lifting heavy objects and such relevant measures. In this study 74.4% mothers took proper rest and sleep during pregnancy. In Bangladesh pregnant mothers were neglected more and their need for sleep and rest were also neglected, even during pregnancy. But due to more awareness and up gradation of women's right throughout the world the situation is changed. The researcher saw in his early life a lot of maternal and neonatal morbidity and mortality which is reduced to a minimum level in the recent period. In 2010, Bangladesh got an UN award for its remarkable achievement in attaining the Millennium Development Goals (MDG) particularly in reducing child mortality rate.

57.8% pregnant mothers were able to avoid sick person and 56.7% mothers didn't lift heavy objects. It indicates that concern about infectious diseases and consequences of lifting heavy objects during pregnancy is still not known to the mothers and their families.

71.1% mothers had no difficulties in transport, it is due to more consciousness in this regard, though it requires more improvement.

It can be said that though the awareness regarding pregnancy and safe development of the fetus is increased among the people, still it is not in all its individual elements and not to its expected level, which requires more effort.

#### **d) Medical Care during Infancy and Early Childhood.**

Mental retardation can be prevented during infancy and childhood by knowing the causes and taking steps to keep children safe and healthy. These may be immunization, injury prevention, newborn screening and treating the condition as far it is possible, reducing the intake of harmful drugs, reducing exposure to lead, mercury and toxins in the environment.

#### **Vaccination during Infancy and Childhood**

In this study it was found 99.1% children were given vaccination. According to some working papers of WHO which were prepared in 2004, as many as 73% of Bangladeshi children were considered to be fully immunized. In 2011, another study showed it to be 86% (Bangladesh Demographic and Health Survey, 2011). In reports of the concerned professionals it was mentioned that Expanded Programme on Immunization or EPI began in 1979 in Bangladesh and it was below 2% until 1985. Then it was developed by the Government of Bangladesh in various phases. EPI is successful in Bangladesh as its current status, mentioned above. It has reduced the neonatal and infantile morbidity by vaccine for preventable diseases. It has significant achievement in comparison with other South Asian countries. Still it has further scope for improvement and Bangladesh Government is trying to reach that goal (Ahmed, 2012). The findings of this study are consistent with the above report and it can be hoped that in future 100% immunization will be possible in Bangladesh.

#### **Childhood Diseases**

74.4% mentally retarded persons suffered from mostly occurring childhood diseases as found in this study. Among these diseases fever, diarrhea and respiratory diseases were more. These findings are consistent with other findings. In Bangladesh it was reported 21% children suffer from respiratory infection, 40% from fever and 8% from diarrhea (WHO report, 2004). The current study shows more prevalence among the mentally retarded persons than the above report of WHO, which was conducted in general population. Respiratory infections are leading cause of childhood illness and death in Bangladesh. According to some UNICEF's reports published in 2006, only 37% of the children took treatment from health care providers and it is lesser among the poor, uneducated and remote rural areas. Diarrhea is also a serious problem for the young children of

Bangladesh. Poor water and sanitation facilities contribute to the spread of diarrhea and respiratory infection. Many parents fail to wash their hands before preparing food and after defecating or cleaning their babies, thus spreading diseases to their children.

### **Modern Screening Tests for Mental Retardation**

Intellectual disability is detected from physical observation and examination, detailed history taking, IQ test and assessing adaptive functioning. But modern screening tests like cytogenetic studies, metabolic investigations and neurological examinations are done for early diagnosis, searching etiology or to prevent and manage the cases. In Bangladesh these tests are just beginning and it is also not affordable by most of the people. In this study only in 18.9% cases screening tests were done. None of the rural cases had the screening tests. So the proper diagnosis of the cases in respect of individual cause and syndrome was not possible in this study. In Bangladesh some rich people go abroad to do the tests. It can be hoped that in near future the modern screening tests will be extended to the primary care level. Proper awareness and initiatives are required in this regard.

### **Head Injury at Infancy & Childhood**

Head injury can cause a wide range of cause consequences e.g. unconsciousness, confusion, drowsiness, fracture of the skull or face, facial bruising, fluid drainage from the nose, mouth or ear, severe headache, personality changes, unusual behaviour, slurred speech, blurred vision, inability to move one or more limbs and in many cases mental retardation can occur. In this study 41.1% cases had history of severe head injury in infancy and childhood. In 52.5% rural and 32% urban cases it occurred. It indicates that the infants and children are brought up in a risky condition in this country and the parents, care givers and family members are not properly aware about its consequences. So negligence is existing in caring the infants and children.

None gave the history of taking drugs which may cause Rey's syndrome. It means unnecessary or harmful drugs were not used, which may be due to the growing concern about the abuse of drugs.

Nearly none of the cases (1.1%) gave the history of exposure to lead or toxic substances in the nearby environment. In Bangladesh people are not duly conscious about environmental pollution. They are always

violating the laws and a principle regarding environmental pollution in various sectors as it is found in newspapers and Medias. But this study shows the opposite picture, which indicates that the condition is improving day by day, though it is not noticed by all. In Dhaka city using of CNG in motor vehicles improved the environments. Smoking and polythine bag is also banned throughout the country. Improvement was observed in other areas, too. It seems that awareness is developing among the people.

## **Medical Care after Detection of Mental Retardation**

Diseases are found more among the people with mental retardation than the others. But they are not duly identified. Some diseases are found as a feature of the causes related with mental retardation. Other diseases occur as they occur among all the people.

### **(a) Diseases Directly Related with Mental Retardation:**

Some diseases are found as a part of the causes of mental retardation. These may be heart diseases, cerebral palsy, epilepsy, vision and hearing impairment, speech and language problem. In this study it was found that only a few number of the mentally retarded persons were diagnosed having diseases related with mental retardation. Among these 10% gave the history of hereditary diseases, 17.8% had neurological diseases, 4.4% had heart diseases, other diseases were reported less. In international studies heart diseases and neurological diseases found to be ranged from 2.8% to 9.0%; heart diseases were found 30% to 40% (Horwitz et al., 2000). In this study neurological diseases were found more and heart diseases were lesser. Probably in these cases neurological diseases (e.g. epilepsy and others) were diagnosed easily, whereas heart diseases were not diagnosed due to lack of access to sophisticated diagnostic tools.

Most of the mentally retarded persons (62.2%) took multiple system of treatments i.e. modern medical treatment along with homeopathy, ayurved and miscellaneous other sorts of treatments. 25.6% took care from specialist doctors and 10% took care from alternative sources of treatment e.g. homeopath, ayurved, faith healers etc. The study indicates that the guardians of the mentally retarded persons suffer from indecision regarding medical care. The ability and availability of taking specialist services are less in the country, which is also evident from this study.



## **(b) General Diseases among the Mentally Retarded persons**

General diseases are also found more in the mentally retarded persons than the others, but they are not always identified. A person with mental retardation may not complain of feeling ill, and the condition may be noticed only because of changes in behaviour. Such behaviour should be understood and encouraged to seek help (Gelder et al., 2006).

In this study, it was found that 82.2% suffered from multiple common diseases. Among the acute conditions respiratory diseases occurred more (8.9%). Other conditions were less severe and those were fever, diarrhea. It is consistent with the findings of other studies in Bangladesh. Kabir (2011) found 67% of children having respiratory problems among 5157 children less than 5 years of age. Rural cases (15%) were more than urban cases (4%) suffering from respiratory diseases. It is due to lack of awareness, care and less availability of modern treatment in the rural areas. From the literature reviews, findings and observation of the pediatricians, doctors of other disciplines, and the researcher it was found that mentally retarded persons suffer more from common diseases than the other people. But in this study such conditions were found lesser than Kabir's study. This may be due to as the mentally retarded persons can't duly express their disease condition and also their care taker can't understand them. Besides these there is negligence of the concerned persons and authorities in this regard and the situation is not upgraded as per demand of the present days. Whereas minor conditions were noticed as they could be solved easily and it was lesser bore some to the caregivers.

Rural (7.5%), poor (11.9%), and low educated (21.5%) took less specialist treatment than their counter group i.e. urban (42%), rich (39.58%) and highly educated (33.33%) respectively. These findings are consistent with our socio cultural background. Usually urban, rich and more educated people are conscious and take more specialist treatment than the rural, poor and low educated people. The urban, rich and more educated people have more links with the modern way of life and also with the modern treatment. The changes and positive aspect of modern medical science is known to them, so they readily go to these services. Whereas, the rural, poor and less educated people are slow and take decision later and unwilling to go to the modern treatment. Also their ability is lesser.

In these cases mothers were influenced more by other than the family members (38.9%) to choose the category of treatment than husbands (37.8%) or parents (21.1%). It indicates that these families were not provided proper knowledge, information or other resources in this regard.

### **Mental Diseases among the Mentally Retarded Persons**

Mental diseases also occur more in the mentally retarded persons than the rest of the population. But it is also not properly diagnosed. In this study majority (75.6%) of the cases suffered from various psychiatric problems (e.g. developmental disorders, schizophrenia, mood disorders, behavioural problems etc.). In many national and international studies it was found that mental diseases occur 3 to 4 times in the mentally retarded persons than the other people (Gelder et al., 2006). In a study MZR Khan (unpublished dissertation, 2010) stated that 47.9% of the mentally retarded children were suffering from mental diseases in a sample of 48 mentally retarded children in Dhaka, Bangladesh. Whereas in a national survey it was found to be 16.05% among the population of Bangladesh. Thus in this study it is consistent with the international findings i.e. mental disease are found more among the mentally retarded persons than the rest of the population.

Considering the findings and discussion with the parents and professionals the researcher understood that the more prevalence of mental diseases in this study may be due to socioeconomic, biological and other possible causes. The mentally retarded persons are more vulnerable to mental illness due to their reduced capacity to manage social and cognitive demands, problem solving difficulties, poor social judgment and communications. They also had biological factors such as higher rates of genetic abnormalities, brain damage and biochemical abnormalities. Psychological factors such as low self-esteem and damaged self-concept are also the causes of mental illnesses. They feel parental and peer rejection, limited support and stigmatization.

Majority of the mentally retarded persons were treated by non-psychiatrists for their psychiatric problems. In Bangladesh, availability of psychiatrists is too much less and the people are also not aware about psychiatric diseases and its treatment. Mental health services are concentrated around tertiary care hospitals in large cities and absent in primary care. The burden of mental disorder is high in Bangladesh, yet a largely unrecognized and under-researched area.

## **B. Psychosocial Care of the Mentally Metarded Persons in Bangladesh**

### **1. Background of Psychosocial Care of the Mentally Retarded Persons in Bangladesh**

#### **1.1 International Perspective**

The United Nations Declaration on the Rights of Mentally Retarded Persons and the Declaration of the Rights of Disabled Persons, in 1970s, which were the first instrument, which made it possible to face the problems of the mentally retarded persons internationally with united effort and it came as an international agenda. During the 1980s it came as right-based issue. It was declared International Year of Disabled in 1981 and the International Decade of Disabled Persons from 1981-1991. It was formulated World Programme of Action (WPA) concerning Disabled Persons adopted by the General Assembly on 3 December 1982, by its resolution 37/52. The programme had three core objectives, prevention, rehabilitation and equalization of opportunities to the persons with disabilities to ensure full participation in social life and national development. In 1993 it adopted UN Standard Rules on the Equalization of Opportunities for persons with disabilities. It was designed with an aim to help policy making and provide a basis for technical and economic cooperation among the states. In September 2000, world leaders adopted UN Millennium Declaration, committing to reduce extreme poverty and setting out a series of time-based targets that have become known as Millennium Development Goals (MDGs). It had eight goals to be achieved by 2015, which are the main challenges for development throughout the world. These are (1) eradication of extreme poverty and hunger, (2) achieve universal primary education, (3) promote gender equality and empower women, (4) reduce child morbidity and mortality, (5) improve maternal health, (6) combat HIV/ AIDS, malaria and other diseases, (7) ensure environmentally sustainable development, (8) develop a global partnership for development.

These goals further have 21 targets and 60 indicators. Although these do not explicitly mention disability, yet they are relevant with the prevention of disability and well-being of the disabled persons. In December 2008, the UN General Assembly adopted a resolution, "Realizing the Millennium Development Goals for Persons with Disabilities through the Implementation of the World Programme of Action Concerning Disabled Persons and the CRPD". It emphasized the realization of the situation of persons with disabilities in relation to

MDGs and implementation of the World Programme of Action (WPA) and the Standard Rules and the CRPD (Convention on the Rights of Persons with Disabilities). Then it was organized the 'Expert Group Meeting on Mainstreaming Disability in MDG Policies, Processes and Mechanisms: Development for All' in collaboration of the UN Secretariat for the CRPD with the WHO. In 2008 'Accra Agenda for Action' committed to develop policies and programmes including the disabled, as per international agreement. (Lored et al. 2010)

## 1.2 Bangladesh Perspective

Before 1977 the term mental retardation was unknown to the people of Bangladesh. Then at that year it formed SCEMRC (Later on SCEMRB and now SWID Bangladesh) by the initiative of some parents of the mentally retarded persons, psychologists, some other professionals and dedicated persons. Thereafter many other organizations were formed e.g. Bangladesh Protibondhi Foundation , SIVUS institute , National centre for Special Education (NCSE), Rehabilitation Institute and Hospital for the Disabled (RIHD), Centre for Rehabilitation of the Paralyzed (CRP), Tori Foundation, GBSS (Gram Bikash Shohaok Sangstha ) etc. (Mamun, 2011, Ferdous, 2009).

Among some of the activities of these organizations and Bangladesh Government are mentioned below.

1. National Coordination: Government and non-Government level: Initiatives of NFOWD.

2. National Disability Policy.

3. Legislation for people with disabilities:

Legislation with the title of Protibondhi Kallyan Ayn-2001(Disability Welfare Act-2001) has been enacted in 2001 for the disabled in the parliament.

4. Census:

According to WHO's estimate 3% of total population of Bangladesh are intellectually disabled. But this is not authentic and reliable. NFOWD and HI have jointly done a prevalence survey on specific areas and found it below 1%.

5. Public awareness:

Through different means disability is now well-known to the people, Government and non-Government organizations are highlighting this issue. Many studies, reports, journals, periodical, flip charts, books,

manuals, and films have been developed in this field to make the people more conscious.

#### 6. Education:

Government and non-Government organizations are arranging special education, coordinated education and other sorts of educational curriculum for the disabled people.

#### 7. Training and Employment

Now Government has made adequate provisions in the National Policies for people with disabilities to create employment opportunities.

#### 8. Family life and Personal integration

The constitution of Bangladesh and disabilities welfare Act ensures family life and integration of people with intellectual disabilities without any discrimination.

#### 9. Regional and International Cooperation

Bangladesh government recognizes the need and importance of regional and international cooperation regarding disability issue. There is now increased participation of the Government in the international conferences, seminars, workshops and many NGOs are working at their best level.

#### 10. Other activities

Besides the above activities it is now providing rehabilitation services, assistive services, self-help programmes, information services to the intellectually disabled persons. Government is also to monitor and evaluate the services and a monitoring committee has formed in this regard by the Ministry of Social Welfare. (Mamun, 2011)

## **2. Findings of the Current study**

### Psychological /Emotional and relevant Problems related with the society

In this study majority (58.9%) of the cases were found to have multiple social problems e.g. they were neglected, avoided and misbehaved. Only neglected in 28.9% cases, avoided in 11.1% cases. It was nearly same in various categories of respondents irrespective of rural, urban, financial or educational status.

There are many reports on society's attitude towards the mentally retarded people. Miles (1983) had written that until meeting the basic needs like food and shelter people didn't feel for other's sufferings. Fear, ridicule, avoidance by the general public and disregard for the disabled persons was commonly found in Pakistan (Abdullah, 1981; Ahmed, 1981; and Miles ,1979a,1981a). The reasons for these were

superstitions and the findings were same in many countries in Asia and Africa (WHO, 1982). Majority (37.8%) of the mentally retarded persons felt difficulties in their daily living and 32.2% felt helpless. In the history, it was found that the mentally retarded people were forced to beg, humiliated, and their livelihood was too much tough (Griffin, McClidock, 2007).

Though majority of the mentally retarded persons are suffering from social problems, but the situation is improving than the previous time, when they were totally avoided by the society and were bound to live inhuman lives. There is now flow of progress due to continuous efforts of WHO, UNICEF, many national-international organizations and the Government (Zaman, et al. 1990)

The majority of the respondents (40%) suggested coordinated initiatives of the Government, NGOs, social organizations, educational institutes and the society to overcome the problems. Their opinion is true, no single authority is unable to solve these problems, rather all should do altogether and then progress will happen.

## **Education**

Majority (48.9%) of the respondents suggested for coordinated and combined education, which is the modern concept also. But many (35.6) also desired for special education.

The modern ideas for education of the mentally retarded persons are not well disseminated in the country. Inclusive education and its positive effects are not well-known to the people. Still the people are in favour of the modern ideas from their common senses. In a study by Zaman and Ara (1990) it was found that those mentally retarded children, who attended normal school along with other normal children, their improvement were better than those who were in special schools. Johnson and Johnson (1986) stated that inclusive education helps in positive interdependence, individual accountability, collaborative skills and group processing.

## **Earning**

66.7 % respondents suggest for special jobs for the mentally retarded persons. 21.1 respondents suggested integrated job. Now a days the concept of supported employment is suggested. In this study majority respondents were found not familiar with the idea. But some

concerned professionals mentioned that the supported/ sheltered employment results in increased productivity, independence and more community integration. In supported employment the mentally retarded persons work with others who are not disabled. As this modern concept is giving positive results it should be informed that the people and motivate them accordingly.

## **Housing**

Majority (37.8%) of the respondents seeks initiatives from the community for housing of the mentally retarded persons. Then many (31.1 %) respondents thought that family will arrange the housing. 28.9% respondents thought Government will make houses for the mentally retarded persons. Here the respondents didn't think for integrated arrangement. But the modern concept is to co-ordinate all the efforts from the family, community and the government (Power, 1989). So the people should be motivated to the modern view, which will be more fruitful.

## **Social life**

74.4 % respondents were in opinion of integrated social life. Once a time there were no care for the mentally retarded persons, then came the era of institutions, which was abandoned later on. Thereafter the idea of normalization is evolved. Throughout the world now it is upgrading. Here the respondents are more in accordance with the modern concept. Experts opine that the community integration is an evolutionary process. It has many steps. The persons concerned with the care of the mentally retarded persons should be trained, skilled and facilities should be promoted (Hill, 1989). Professionals and system must change their traditional mindsets by fostering self-sufficiency, and reducing dependency if citizen with disabilities are to become truly integrated in the society (Medlin, 1989).

## **Recreation**

65.6% respondents believe that there should be integrated arrangement for recreation for the mentally retarded persons. Previously the issue of recreation for the mentally retarded persons was not highlighted. Now the question raised and the majority of the respondents of this study answered which are same as the modern view. In the present situation there are national and international arrangements for the

recreation of the mentally retarded persons, but they are limited and not duly coordinated and integrated in the society. Like community integration arrangement for recreation also requires mastering certain skills and activities in the vocational and domestic living domains, the ability to deal constructively in this regard. It has been considered as an important predictor of successful community adjustment and has positive effects on job and domestic living (Schleien, 1989).

### **Role of Various Organizations and Government for Medical and Psychosocial Care of the Mentally Retarded Persons**

In 45.6% of cases the services came from the families, relatives and neighbours; 32.2% cases get services from the NGOs and 22.2% get Government services as it is found in this study. It indicates that the government and society is not duly conscious about the pain of the families having mentally retarded persons. Throughout the world now it is thought that families alone can't cover all the aspects of care for the mentally retarded persons. They require help from the society, NGOs and the Government. It should work on a partnership basis. The persons concerned with the care of the mentally retarded persons should change their views and work forward with due preparation.

The researcher observed that majority of the respondents don't possess systematic knowledge about mental retardation and its care. Scientific knowledge is not well circulated and most families feel helpless in this regard. There are lacking in service providers and their abilities are also limited.



## Evaluation of the Services

Majority of the respondents (35.6%) evaluated the services as poor, 21% as very poor, 17.8% called it of high quality and 14.4% mentioned it nearly high. The services for the mentally retarded persons are not to its expected level throughout the world and it is similar also in Bangladesh. Medical science is continuously developing, but access to it is lesser for the mentally retarded persons. It is similar in case of psychosocial and all other services. The family members and relatives of the mentally retarded persons feel it deeply when they seek services. So most of them are disappointed and evaluated the services as poor in Bangladesh. But time has come to change the views. It should be uplifted the services, the humanitarian motivation should be higher, social bondage should be deepen, and the level of civilization should be upgraded.

The respondents expected that the services should be upgraded both in qualities and quantities. Throughout the world services are gradually upgrading. Bangladesh Government, NGOs and all other concerned authorities and persons are trying but yet it is not up to its level. The efforts should be increased and expanded.

Before entering into the conclusions, the researcher wants to give the following information. His research supervisor during 1986-1990 interviewed about 2000 mothers of different socioeconomic conditions. All the mothers where asked, 'do you sometimes feel as if it would be better if your mentally retarded child die normally before your own death'? About 90% mothers said YES.

The researcher also asked the same question to all the 90 mothers he interviewed. Almost 70% said NO.

The researcher understood that these YES and NO answers project the changing pattern of **MEDICAL AND PSYCHOSOCIAL CARE OF THE MENTALLY RETARDED PERSONS IN BANGLADESH.**

## Conclusion

From the findings and discussion it can be concluded the followings.

- (1) Awareness about mental retardation and its care is increasing in the country but it is not to the scale.
- (2) Some aspects of medical care is encouraging e.g. EPI programme, check up during pregnancy, nutrition to the mother. Whereas, in many other aspects it is below standard e.g. screening tests for detecting mental retardation, neonatal and pediatric care.
- (3) Specialized in-depth medical care facilities targeting only the mentally retarded persons yet not developed in Bangladesh.
- (4) The parents and other caregivers yet do not possess adequate knowledge for caring the mentally retarded persons.
- (5) The issue of psychosocial care is too much less understood or neglected by the parents and the community.
- (6) Though care for the mentally retarded persons is initiated by the Government and non-Government organizations still it is limited in few areas of the of the country and not extended to each and every doors of the mentally retarded persons.
- (7) Modern medical and psychosocial approach is still not duly adopted and extended in the care for the mentally retarded persons.
- (8) The care for the mentally retarded persons is scattered and not in due discipline and well organized.
- (9) Poverty, illiteracy and stigma are prevailing among the people, though it is gradually reducing. People's attitude is changing towards a positive one; still it remains a long way to reach the goal.
- (10) Long term National Policy is needed in relation to health, education, employment, housing and social security of the mentally retarded persons.

## Recommendation

Considering the literature review, the case studies and discussion with the experts, the researcher recommends the followings in relation to the medical and psychosocial care of the mentally retarded persons in Bangladesh.

1. Preventive measures for mental retardation should be extended all over the country,
  - a) Each and every pregnancy and labour should be cared by qualified medical personnel.
  - b) Immunization programme should be compulsory for all the mother and their children.
  - c) Genetic screening tests should be facilitated and extended.
  - d) Measures for prevention of mental retardation should get more priority.
2. There should be a separate special discipline in medical system of the country for mental retardation which will deal with the prevention, treatment, care and research on mental retardation.
3. There should be a section in the Ministry of Social Welfare which will coordinate all over services for mental retardation both nationally and internationally.
4. Research in biological field to prevent and treat mental retardation should begin and upgraded properly in the country.
5. To create awareness and provide knowledge to the people about mental retardation and its care, all the Medias should be utilized.
6. In educational curriculum there should be lessons on mental retardation.
7. The issue of care to the mentally retarded people should be upgraded from welfare based approach to right based and development based approaches.

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