

Mental Health Problem among Persons with Disability



A dissertation

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I hereby declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research. I, also certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text of the thesis.

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March, 2018

ABSTRACT

This qualitative research employed a grounded theory approach to explore the nature of psychological problems in people with disability. This study also explored the developmental process of these psychological problems. This study included three types of disabilities namely physical, visual, and hearing & speech disability. In depth interviews were conducted with nine participants, among them three had physical disability, two had hearing & speech disability and four had visual disability. There were five male participants and four female participants. Participants were selected using purposive sampling strategy from different organizations and personal contact. In-depth interview data were analyzed using the qualitative data analysis software NVivo-10.

The findings revealed several mental health problems exist among person with disability. These mental health problems are helplessness, devalued, uselessness, burden, neglected, sadness, numbness, suicidal thought, avoidance, abusing drug etc. It was developed through a three sets of perspectives. They were found as the main contributors of the perception of disability. These were family view, social view and self view. Real life issues also played an important role in the development of these views and mental health problems. Researcher also found there was a common conception about disability that portrayed disability as dependent, incapable, inanimate and discriminated. This conception is vice versa. The family view, social view, self view and mental health problems make the conception and the conception of disability also help in their creation. This study helps one to understand the developmental process of mental health problems. By this, professionals can formulate a client and facilitate the development of the current treatment practice as to better assist the people with disabilities. It provides an insight in dealing with disability with higher efficiency.

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DEDICATION

To my beloved

Little sister

Rifa Tasfia Rouf (Tuba)

CHAPTER 1

INTRODUCTION

According to World Health Organization disability is a multi-dimensional concept that arises from the interaction of health conditions and the environment (Organization, 2001). Along with these two sets factors (i.e., physical and social), acknowledgement and exploration of psychological factors are crucial in the understanding of disability. However, attention to the understanding of psychological aspects of disability has always been very limited. Disability occurs for many cause such as accident, wrong pathological diagnosis, malnutrition of pregnant women, lack of trained birth attendants and nurses, polio, typhoid, violence, acid burn, marriage between close relations, babies not being vaccinated and also because of lack of knowledge and awareness among care providers (Bickenbach, 2011)

Grech (2009) found that 80% of people with disability live in developing country and there is a strong link between disability and poverty. Poor people are more vulnerable toward disability, and people with disabilities are the poorest. Most of the persons with disabilities are often deprived of basic needs including health care, housing, education, employment and other opportunities. A study compared groups, person with disability and person without disability, and found that person with disability reported to have lower educational attainment, lower employment rates and lower income (Gannon & Nolan, 2004).

Crocker and Major (1989) study indicated that people had stigmatizing attitude towards people with disability. These stigmatized attitudes contribute to discrimination for people with disability. Many people with disability view themselves as inferior or as a burden (Weinberg-Asher, 1976). In Bangladesh, a huge amount of people with physical disability

cannot participate in current development activities. Because of this, the nation is losing their possible contribution in the national development. They are deprived from getting equal rights and opportunities in due to discriminated attitude in the society. There are government policies for them in education and treatment, but they do not get it properly. Persons with physical disability also find difficulty to get into buses, trains, and other forms of transports, however, there is very little supportive structures to help them in this respect. These difficulties suggest a picture of stressful life of a person with disability which is likely to create vulnerability for mental health problems among the person with disability. A research about physical disability and mental health found that physical disability increases the risk of psychiatric disorder (Turner, Lloyd, & Taylor, 2006). According to world health organization the mental health has been recognized as an international priority (Health & Abuse, 2005). An important part for ensuring mental health for all should be to include psychological needs of people with disabilities as well.

Before proceeding in the study of people with disability, it is essential to understanding the concept and classification of disability, which has been presented in the following section. Prevalence of disabilities has also been presented in the subsequent section. Theoretical understanding of disability has also been presented. Impact of disability as well as the rationale and objectives of the study have been presented towards the end of the introduction section.

1.1 Disability

The term disability can be understood through the interaction of family, society, person and the experience of disability itself. Disability is a complex concept; understanding

of it requires knowing the nature of disability, the impact and consequences of disability, experiences of disability as well as conception of disability in the society, family and the person.

1.1.1 Definition. This term disability is used to address a wide range of impairment and problems including, physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness.

According to Oxford Dictionary “disability means a physical or mental condition that means you cannot use a part of your body completely or easily or you cannot learn easily or a physical or mental or permanent disability”. World Health Organization defines disability as “Disability is an umbrella term, covering impairments, activity limitations and participation restrictions. Impairment is a problem in body function or structure on the other hand an activity limitation is a difficulty" (Rosenbaum & Stewart, 2004). Commonly disability is defined by a physical or mental impairment but sometimes it is also defined by the cultural norms. This study is focused on physical disability which includes impairment of physical organ.

1.1.2 Classifications. Previously we discuss about definition of disability. It is also important to understand the classification of disability. The Ministry of Social Welfare of Bangladesh proposed the Disability Welfare Act of 2001 where thorough classifications along with relevant definitions of disabilities have been proposed. They proposed seven different categories of disability presented in the Table 1.1.

Table 1.1.

Definitions of classification of Disabilities

Classifications	Definitions
Persons with Disabilities	Who are physically disabled either congenitally or as a result of disease or being a victim of accident, or due to improper or maltreatment or for any other reasons became physically incapacitated or mentally imbalanced as a result of such disabled-ness or mental impaired-ness has become incapacitated, either partially or fully and is unable to lead a normal life
Persons with visual impairment	No vision in any single eye, no vision in both eyes, visual acuity not exceeding 6/60 or 20/200 (Snellen) in the better eye even with correcting lenses or limitation of the field of vision subtending an angle of 20 (degrees) or worse
Persons with physical disabilities	Lost either one or both the hands, lost sensation, partly or wholly, of either hand, lost either one or both the feet, lost sensation, partly or wholly, of either or both the feet, physical deformity and abnormality, permanently lost physical equilibrium owing to neuro-disequilibrium
Persons with a hearing impairment	Loss of hearing capacity in the better ear in the conversation range of frequencies at 40 decibels (hearing unit) or more, or damaged or ineffective hearing abilities
Persons with speech impairment	Loss of one's capacity to utter/pronounce meaningful vocabulary sounds, or damaged, partly or wholly or dysfunctional
Persons with a mental disability	One's mental development is not at par with his chronological age or who's IQ (Intelligent Quotient) is below the normal range, or has lost mental balance or is damaged, partly or wholly
Persons with multiple disabilities	People who suffer from more than one type of impairment stated above.

Although that, World Health Organization announced standard terminology to make a distinction between impairment (physiological), disability (personal) and handicap (social). These are presented in exact form in the following,

- An Impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.
- A Disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being;
- A Handicap is a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal depending upon age, sex, social and cultural factors, for that individual.

From the discussion presented above we see that there are different types of disability which can be organized into four broad categories, physical, hearing & speech, visual and intellectual disability. This research only chooses the first three categories. People with intellectual disability were not included for this research. Because intellectual disability is part of the classification system for mental health problems. However, the other three types of disability are only discussed in terms of physical health problems. Therefore, studying psychological impacts for these three types of disability is likely to contribute by including psychological aspects in addition to physical health aspects.

1.2 Prevalence rate of disability in World and Bangladesh context

Disabilities exist in all corner of the world, irrespective of bearing a developing or developed status. The following section presents prevalence of different types of disability around the world and in Bangladesh.

1.2.1 World context. According to the World Health Organization (2004) there were 6500 million people in the world of which an estimated 100 million are believed to be moderately or severely disabled (Rosenbaum & Stewart, 2004). The overall rate of people with disabilities is estimated at 12.6% in the United States. It also suggested that one in every five adult individuals has one form of disability (Courtney-Long et al., 2015). Globally, it has been reported that the rate of disability for female is 11% higher than the rate of disability for male (Group, 2004). In Sri Lanka prevalence rate of physical disability was 4.2% among all disability. They also reported a higher rate of physical disability among the people at the age group of 40-59 years (Peiris-John et al., 2014).

1.2.2 Bangladesh context. Individuals with disability are one of the most vulnerable and disadvantageous section of the society in Bangladesh. According to a study of Faruque et al. (2008) the estimated number of individuals with disabilities is 10% of its total population. Other source reported a higher prevalence of disabilities (14%) among adult population in Bangladesh. Some estimated the size of disabled population at 10 million in Bangladesh ("DISABILITY IN BANGLADESH: A Situation Analysis," 2004). A detailed estimate of different types of disability is presented by the Bangladesh Bureau of Statistics (source: Statistical Pocket Book of Bangladesh, 2013). These are presented in the following page.

Table 1.2

Disable Person by Types of Disability in Bangladesh, 2011

Disability Type	Population Number	Percentage
Speech	275,594	13.60%
Vision	394,020	19.45%
Hearing	183,012	9.03%
Physical	796,219	39.30%
Mental	254,439	12.56%
Autism	122,558	6.05%
Total	2,025,842	

Note. Population & Housing Census, 2011, Bangladesh Bureau of Statistics.

In the study, Disability in Bangladesh Prevalence, Knowledge, Attitude and Practices found that 5.6% people in Bangladesh have a disability of one kind or another (Titumir & Hossain, 2005). It also revealed that the people living in Char or Haor areas in Bangladesh have high rate in disability. In this area 7% people have at least one kind of disability. The prevalence rate of impairment is a little lower in Hill tracts areas and coastal areas. Percentages of different types of disability among the persons with disabilities were, hearing disability 18.6%, visual disability 32.2%, speech disability 3.9%, physical disability 27.8%, intellectual disability 6.7% and multiple disability 10.7 percent. Another study of G. M. Hosain (1995) found that overall prevalence of disability was 8.5% and major forms and percentages were hearing disability 23%, visual disability 21% and movement disability 15%. Action Aid also conducted a survey on Person with Disability in Bangladesh. The study found

that among the persons with disability 42% were physically impaired, 20% were visually impaired and 20% were speech and hearing impaired (Sultana, 2010).

1.3 Theoretical understanding

There are two main approaches that are popular worldwide for understanding as well as working with disability. They are medical model and social model. These two models basically made for policy making.

In medical model, disability is viewed as a problem of the individual person. Disabilities are caused by disease, trauma, or other health conditions and the person with disability requires sustained medical care in the form of individual treatment by professionals. Medical model assumes that the first step solution is to find a cure for person with disability. This model pay less attention on disabled individuals' opportunities to make choices, control their lives and develop their potential (Brisenden, 1986).

The medical model creat some set ieads in the mind. Because the condition of a person with disability is medical, so the perception about them will be they are ill health and they are less productive. Normally when people are sick, they have no obligations of society like going to school, getting a job, taking on family responsibilities, etc. and these restriction is applicabile for people with disability. According to this model, the individual has the problem, not society and the individual should provided different interventions like the appropriate skills to rehabilitate or deal with it. Therefore by this model people of society judged people with disability as they are differently. So, discrimination, stigma these kind of concept made by this model. Under this model most disability policy issues have been regarded as health issues, and physicians have been regarded as the primary authorities in this policy area.

However this is clear that there is no concern about psychological issues of people with disability.

Another approach is social model. According to this the social model, disability is constructed by social expectations and institutions rather than biological differences. The social model of disability views disability as a socially created problem. In this model, disability is not a characteristic of an individual; it is a complex collection of conditions created by the social environment. The management of the problem with disability requires social action. It is created by the society so they should take responsibility in which limitations for people with disabilities are minimal. According to the social model, equal access for someone with a disability is a human rights concern. Under this idea, disability is not defined by the physical features of the body but by a deviance from the social convention of health. Social model's philosophy originates in US civil rights movement and has been supported by The British Council of Organizations of Disabled People and Rights. The social model has been developed with the aim of removing barriers so that disabled people have the same opportunity as everyone else to determine their own life styles (Shakespeare, 2006).

From further discussion we understand that the models are about how the people with disability treated, how they viewed and what kind of facilities they got from others. But there is no concern about psychological issues. How the person with disability feel, what kind of mental health problems they have or how this problems developed this things are not mentioned in those models. These two models are focused on physical health and social issues. But there is no psychological model of disability. Given this degree of understanding, our future objective should be to develop and operate a cluster of models, which will empower people with disabilities, giving them full and equal rights together with their fellow

citizens. So this present study can contribute as a first step to develop a full psychological model for person with disability.

1.4 Impact of disability

Disabilities among people come in various forms and each individual experiences his/her disability differently to others. Even after, they are diagnosed with same medical condition. In the same way, having a disability can have different impact on different individuals. The study of “Impact of Disability on Quality of Life of Rural Disabled People in Bangladesh” revealed that having a disability have a devastating effect on the quality of life. Particularly disability made a negative effect on their marriage, educational attainment, employment, and emotional state. Therefore disability has impact on different aspects of their life. These impacts of disability are discussed below.

1.4.1 On self. Disabilities have negative impacts on the individual. It might stop them from engaging in activities that they would like to become involved in. This might have a demoralizing and negative effect on an individual’s mental health, self-esteem and confidence. Some disabilities require constant monitoring, hospital visits, operations, doctor’s appointments or support from those around them. They also takes the help of modern technology for communication, like wearing hearing aids or glasses, or using speech to text devices to express their thoughts. This dependency on others can be stressful and often lead to a lack of control over an individual’s life and life choices.

People with disability learn how to adapt with the disability in order to reduce the negative impact they can have on them. Some react negatively and thus their quality of life is negatively affected. Others choose to focus on their abilities as opposed to focusing on their

disabilities and continue to live a productive life. A study about psycho-social characteristics of blind and deaf male student found that the main problem among blind students was difficulty in mobility while difficulty in communication with people was the main problem among the deaf student. (Abolfotouh & Telmesani, 1993)

In addition, if the meaning of disability to the person is negative then they are more likely to feel that they are defined by his/her disability and thus it will have negative impact. Physical disability contributed to enhance stress that increase risk for the occurrence of psychiatric or substance use disorder (Noh, 1988). If the person with disability receives good support from family, a significant other, friends, or social groups then he/she will have an easier time coping with a disability.

1.4.2 On family. Families having a person with disability experience both positive and negative impacts. Family tries to cope with disability. However, having a person with disability in family can also be a source of frustration between spouses and between parents and children or among different members. It can affect all aspects of family functioning. On the positive side, it increases family members' awareness of their inner strength, improves family unity, and encourages connections to community. On the contrary, while caring a person with disability, physical and mental demands, financial and time cost, can have an extensive effect. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial ability of the family and the resources that are available.

For families, caring for a family member with disability may increase stress and affect decisions about work, education, having additional children. It may be connected with guilt,

blame, or lower self-esteem. The expensive medical care and other services may be overwhelming. All of these potential effects could have influence for the quality of the relationship between family members, their living arrangements, and future relationships and family structure.

Families sometimes need short break. Short Breaks give them a break from their role as caregiver and also provide their family member an opportunity to be with others and benefit from new experiences. One of the researches carried out by UCC Science Shops where parents spoke about the pressure on them as caregiver (Balfe, Keohane, O'brien, & Sharp, 2017). They told that they had a lot of pressure and it was a hard job. Sometimes they did not take break from their role.

1.4.3 On society. Disability has a great impact on society. For many people with disability, it is not the disability itself that affects negatively on their lives but the responses they receives from the society has more impact. A person with disability finds it difficult to get necessary social support and required social skills like communication, efficiency, relationships etc. As a result, he/she might face limitations in interacting with colleagues at work, fellow students and family members. In our society, peoples still hold stereotypical view toward people with disability. One study found that social and cultural barriers prevent certain groups of people with disability to utilize health service (GM Monawar Hosain & Chatterjee, 1998). According to Underwood (2002) more than half of the people with disability were treated negatively by the society. There are many plans and programs to ensure that people with disability can easily obtain basic requirements like accessing official places, receiving education, seeking employment and social services, but in

real situation there are huge difference between services for those with disability and for those without disability.

1.5 Mental health aspect of Disability

Mental health is the major concern of this research. The World Health organization defines mental health as, "A state of well-being in which every individual realizes his or her own potential, can cope with the normal stress of life, can work productively and fruitfully, and is able to make a contribution to her or his community". It explains that mental health is not only about the mental health related problems or disorder, but also about coping capability, productive work and contribution in society. Therefore, our mental health is a combination of emotional, psychological and social well-being. It directly affects our thinking, feeling, and behavior. As a result, mental health plays an important role at every phase of life.

1.5.1 Definition of mental health problems. Exact definition of term like mental health problems, mental disorders or mental illness is still ambiguous. (Sawyer et al., 2000) found that mental health problems create a change in thinking, mood or behavior. These changes are associated with distress or impaired functioning. In other terms, mental disorders make disturbance in thought and behavior. For that, they cannot do their daily work effectively. Many people experience mild level of mental disorder or some symptoms of mental disorder that does not diagnosed as mental disorder. In this case, it is defined as mental health problems. Many factors contribute to create mental health problems, for example biological factors, traumatic experience, family history of mental health problems etc.

1.5.2 Determinants of mental health problems. There are some areas like emotional, physical and social, from which indicator of mental health problems are found. According to World Health Organization (2004), the social determinants of mental health were life course, parent, families and household, community, local services and country level factors. There are also some emotional indicator that measure mental health problems like inconsistent thought patterns, frequently changes in mood, lack of interest in social gathering, lack of empathy, inability to tell the difference between reality and fantasy or an apparent lack of control. Usually mental health problems do not cause physical symptoms but sometimes symptoms of a mental health problem become visible physically, such as stomach pain, back pain, headache, or other unexplained aches and pains. Mental health disorder like depression is also an indirect cause for some physical symptom like weight loss, fatigue and loss of libido.

The signs and symptoms of mental health problems depend on the disorder, situation and other factors. Mental health problems mainly affect on emotions, thoughts and behaviors. In a study of Zola (1993) indicates that hectic stress, chronic injure and social support was the significant determinants of depression in people with disability. There are some basic examples of signs and symptoms of mental health problems. They are, sad or down feelings, confused thinking, concentration problem, excessive fears or worries, guilt feelings, severe mood changes of highs and lows, withdrawal behavior, significant tiredness or low energy, sleeping problem, hallucinations, delusions or paranoia, lack of ability to do daily work or handle stress, unable to understanding a situations, abuse drugs, eating problem, changes in sex drive, excessive anger, hostility or violence behavior and suicidal thought or ideation. (Allen, Balfour, Bell, & Marmot, 2014)

In this research mental disorder is used to describe a set of symptoms that are clinically diagnosable under the Diagnostic and Statistical Manual of Mental Disorders (Edition, 2013). Mental health problems used to include both diagnosable mental disorders and symptoms of mental illness that may be sub-clinical. These guide line helped to find out the nature of mental health problems and how it developed among persons with disability.

1.6 Research review and Knowledge gap

This study is mainly concerned with the mental health problem faced by people with disabilities. In the following section, the discussion explains about existing research in this field and the lack of empirical studies. The personal and social costs of mental disorders are significant throughout the world. Globally, mental disorders are the reason for 20% of the total burden of disease. While depression alone is the number one contributor to non-fatal burden of disease and disability for both high and low/middle income countries (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006; Prince et al., 2007). Moreover severe disability is associated with mental health disorders (Scott et al., 2009). When physical disability exists alongside with mental disorder, then it becomes more difficult to handle and also expensive too. So mental health of people with disability is a concerning factor in order to provide them a better service.

According to many research some mental health disorder is common in people with disability like depression, anxiety, affective disorder, substance abuse disorder etc. For example, The National Mental Health Survey in Australia found that 29% of people with disabilities reported anxiety disorder and 17% reported an affective disorder. Where people with no disability were reported 12% anxiety disorder and 4% affective disorder. (Australia,

2008). A study about psycho-social characteristics of blind and deaf male students in Abha City found that among blind student depression was more prevalent almost 14% where among the deaf student depression was 6.5%. (Abolfotouh & Telmesani, 1993). In a study of American Sociological Association, people with disability are at high risk for depressive symptoms. This longitudinal analysis of the study showed eventful stress, chronic strain, mastery, and social support to be significant determinants of depression in this population. Physical disability appears to represent a dimension of stress that increases risk for the occurrence of psychiatric or substance use disorder. (Noh, 1988).

To know about disability there were a series of studies in Bangladesh conducted by G. M. Monawar Hosain. The first study was “Disability problems in a rural area of Bangladesh”. The study found that overall prevalence of disability was 8.5% and major forms were hearing disability (23%), visual disability (21%) and movement disability (15%) (G. M. Hosain, 1995). The 2nd study was “Health care utilization by disabled persons: A survey in rural Bangladesh”. The study found that social and cultural barriers prevent people with disability to utilize health service. (GM Monawar Hosain & Chatterjee, 1998). And the 3rd study was “Impact of Disability on Quality of Life of Rural Disabled People in Bangladesh”, in this study examined the impact of disability on the quality of life of disabled people in rural Bangladesh. The study revealed that disability had a devastating effect on the quality of life of the disabled people with a particularly negative effect on their marriage, educational attainment, employment, and emotional state (Underwood, 2002)

Another study conducted in Bangladesh "The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh" aims to determine the quality of life (QOL) and general mental health of leprosy patients compared with the general population.

Study found that QOL and general mental health scores of leprosy patients were worse than those of the general population (Tsutsumi et al., 2007)

The study "Quality of Life among Persons with Physical Disability in Udupi Taluk" found that among the study participants, 36.2% had a congenital disability. The second common cause of disability was found to be post polio residual paralysis as it was found among 26.2% participants. Quality of Life or QOL score was found to be low under the psychological domain reflecting on negative feelings, bodily image, appearance, spirituality, and self-esteem of respondents (Kuvalekar et al., 2015)

From reviewing these studies it is clear that most of the study in our country was applying quantitative method and these studies are based on questionnaire with definite format. Some study is based on a specific group of people with disability (Kuvalekar et al., 2015; Tsutsumi et al., 2007). Some study is conducted to find out the percentage of people with psychological problem in disability. Similarly, some study is to assess the prevalence rate of disability, types of disability, causes of disability or risk factor for physical disability (Moschioni, Antunes, Grossi, & Lambertucci, 2010). Few studies are conducted based on the rights and laws applicable for people with disability. (Hasan, Muhaddes, Camellia, Selim, & Rashid, 2014; Sultana, 2010). Also, some studies are conducted based on rehabilitation service, vocational training project for people with disability (Heinemann, Linacre, Wright, Hamilton, & Granger, 1994; Nuri, Hoque, Waldron, & Akand, 2012). In Bangladesh, most of the researches assess the quality of life of people with disability. In research based on quality of Life, psychological component is a part of the assessment. In overseas many researches are conducted on psychological issue of people with disability. However, very few researches are based primarily on psychological issue. In Bangladesh, most of the researches findings are

indicated about the association of psychological problem with disability or what type of psychological problems are common among them. Therefore, no study has been conducted to find out the nature of psychological problems or its development in people with disability.

Whenever discussion was about people with physical disability, most of the times, major emphasis is given on physical symptoms, treatment, quality of life, rehabilitation etc. Psychological issues are less prioritized in this scenario. Situation of our country is different from developed countries. A person with disability faces a hard time to cope with the difficult situations. They are exposed to various psychological issues, which leads them to psychologically vulnerable. So an in-depth study on psychological issues faced by people with disability has yet to be carried out. Such in-depth knowledge is of utmost importance before planning any intervention strategy for people with disability.

1.7 Rational of the study

A mental health problem among people with disability is largely an unexplored domain. Only handful of studies has been conducted in this area in Bangladesh. The study findings mentioned in the previous sections does not provide much detail on how mental health problems developed among people with disability. Still many questions regarding contributory factors, developing process need to be explored. Therefore to understand the psychological issues of a person with disability and to make a proper interaction with him there are a lot of areas to explore. To ensure proper care and support for person with disability all these conditions should be considered. So this study would explore the nature and impact of psychological problems among person with disability and factors associated with psychological problems. This study may focus attention towards the importance of

incorporating psychological services for the person with disability and may also guide the policy makers in decide suitable strategies to curb the psychological problems among them. Furthermore this study would highlight the potential areas for future researches.

1.9 Objective of the study

The study aimed to achieve three objectives presented in the following,

1. To understand the nature of psychological problems
2. To explore the contributing factors of psychological problems
3. To explore the developmental process of psychological problems among individuals with disability.

CHAPTER 2

METHOD

2.1 Research design

This study employed qualitative research design using grounded theory approach, which seemed to be best fitting for the purpose. The purpose of the study was to understand the experience, perspective, and mental health of people with disability. Apart from sporadic anecdotal reports, little is known about the nature of the mental health problems and how it developed among people with disability in Bangladesh. Qualitative method is especially suitable for exploring the unknown and therefore this method was used in this research to ensure deeper understanding of the topic.

Grounded theory has been described as a method of discovering theory in social research from thoroughly obtained data (B. Glaser & Strauss, 1967). It is a highly systematic research approach for the collection and analysis of qualitative data for the purpose of generating explanatory theory that enhance understanding of social and psychological phenomena (Chenitz & Swanson, 1986). Grounded theory has been defined by as a systematic process of data collection and analysis leading towards closely linked hypotheses regarding specific concepts (B. G. Glaser, 1998; Strauss & Corbin, 1998). They propose that the roles of theory are to enable prediction and explanation of behavior, be useful in theoretical advancement, be useable in practical applications and guide research on behavior.

Grounded theory method is well suited for exploring the interrelations between different constructs and consequently, developing theory from accumulated data. In this

context, a grounded theory based exploration was used to find the nature of mental health problems and how the problems developed through disability.

2.2 Participants

Person with three types of disability - physical disability (physically lost or lost motor functioning in either or the entire limb), hearing and speech disability (Loss of hearing capacity or damaged or ineffective hearing abilities) and visual disability (no vision in one or both eyes) were selected as participant for this study.

2.2.1 Inclusion criteria. Participants with following two criteria were allowed:

1. Age above 18 years
2. Participants must have any one of the following.
 - Physical disability
 - Hearing and speech disability
 - Visual disability

The first criteria ensured that participants were adult and second one was for that participants had one of the disabilities.

2.2.2 Exclusion criteria. The following two exclusion criteria were used.

- Non communicable
- Seriously ill persons

These two criterions were used to ensure that participant did not have severe physical or psychological problem that can distort his or her thinking process and ability to interact and communicate with the researcher.

2.2.3 Sampling technique. Data was collected through purposive sampling. Researcher selected participants according to the purpose of the study. Sample was collected from personal contacts and different organizations that were working with people with disability. Maximum variation sampling was ensured during the process of recruiting participants. Two main concepts guided the collection of sample; these were theoretical sampling and saturation.

Theoretical sampling. In theoretical sampling the emerging theory guides the sampling (B. G. Glaser, 1998; Strauss & Corbin, 1998). The selection of the participant was based on theoretical sampling. Theoretical sampling is the process of data collection where the researcher simultaneously collects, codes and analyzes the data in order to decide what data to collect next. In this research sample were selected according to memo and hypothesis generated during ongoing analysis.

Saturation. When same information kept coming back without adding any significant amount of new data, such situation is termed as saturation and the researcher can stop data collection when saturation is reached. In this research, researcher guided by this concept through data collection.

2.2.4 Participant characteristics. Maximum variation was tried in the selection of the participants. Nine interviews with individuals with physical, visual, and hearing & speech disability were conducted. Among them three had physical disabilities, two had hearing & speech disability and the remaining four had visual disability. There were five male participants and four female participants. Four of the participants were from urban area and five were from rural area. Six of them were involved with an organization and three of them

had no involvement with any organization. In below there is a tabular representation of demographic information of participants.

Table 2.1.

Demographic information of the participants

Variables	n
Persons with Disability	
Person with Physical disability	03
Person with hearing & speech disability	02
Person with Visual disability	04
How the disability developed	
Accidental	05
Congenital	04
Gender	
Male	05
Female	04
Level of education	
No formal education	01
Up to primary education	02
S.S.C	03
Above	03
Age M(range)	20-65
Monthly income M(range)	0-50,000

2.3 Ethical issues

Ethical guideline of conducting the research was strictly maintained. Written informed consent was used for physical and speech & language disability while, verbal consent was

taken for participants with visual disability. Researcher provided explanatory statements to the participants. Information about the nature, purpose and future utilization of the research were provided to the participants. All the participants either read it or the researcher read it aloud for them (in case of illiteracy and visual impairment) before conducting interview. Participation in the interviews was voluntarily and the participants were informed about their rights to withdraw from research any time.

Participants were also ensured about the confidentiality. For this research, privacy and confidentiality of the participants were given a high priority. All interviews were conducted in a private place designated by the participants according to his/her comfort and convenience. A code number was used for each interview to separate identification for ensuring confidentiality of the participant. During transcription process all the identifiable information in the interview were removed. All the research assistants involved in transcribing data were provided detailed orientation on research ethics and confidentiality.

2.4 Data collection method

For current study, researcher choose in-depth interview as the primary data collection method. Additional information was collected using "key word" and observation method.

2.4.1 In-depth interview. In this study in-depth interview was chosen as data collection method. It is an open-ended discovery-oriented method. In-depth interviews involved not only asking questions, but the systematic recording and documenting of responses coupled with intense probing for deeper meaning and understanding of the responses. In-depth interview in this research was focused and explored the issues in as much detailed as possible.

2.4.2 Supplementary methods. Two additional methods namely "key word" and observation were used to enhance the quality of research data. These two techniques are discussed in the following.

Key word. In this research, researcher used a key word list as an additional tool. There were five Bengali words (see Appendix E), one of them was emotionally attached to person with disability. Researcher used this word to find out perception, feelings, thought and attitude associated with the word of persons with disability. It helped the researcher to explore the unspoken attitude and feeling of person with disability about their disability.

Observation. Observation method was also used as an adjunct method to collect information. It was conducted during in-depth interview in an informal manner. No systematic observation was carried out.

2.5 Instruments

A few instruments were used in aiding the interview process. These include demographic questionnaire, topic guide and voice recorder.

2.5.1 Demographic questionnaire. Interviews started with collection of demographic information from the participants. It helped in building rapport along with collection of basic knowledge about the participant. It contained questions on some basic information such as name, age, gender, type of disability, socio-economic status. Nature of disability (congenital or acquired) was explored along with history of treatment received, information about family etc.

2.5.2 Topic guide. An interview topic guide was developed to cover a range of aspects related to psychological state and functioning (see Appendix D). A topic guide usually has a list of key questions the interviewer plan to cover. It included mostly semi-structured questions. It is very important to devise the right question to ask. With some useful prompts, it encouraged the interviewee to talk about deeper and specific issues.

2.5.3 Voice recorder. A digital voice recorder was used to record all of interviews. Then data was transferred to computer and transcribed in textual form.

2.6 Data collection procedure

Participants were selected purposively through personal contacts with organizations. Data were collected from three organizations, Gram Bikash Sangstha, Society of Deaf & Sign Language User and Kriya Female Rehab Center. At first time researcher communicate with Gram Bikash Sangstha at Bogra. That organization works with different types of people with disability. Researcher interviewed four participants with the help from this organization. Another organization was The Society of Deaf & Sign Language User, which is run by Sign Language Users. They work with sign language. Two participants were interviewed through this organization. One participant was interviewed through Kriya Female Rehab Center. This center works with female drug users and psychologically ill clients. From personal contacts two of the participants were interviewed for the research.

Before taking interviews, consent of the participants was taken both verbally and in written form. Every participant was also provided with an explanatory statement paper. At the beginning of the interview, demographic questionnaire was filling up. In depth interview was taken with the help of topic guide. As per the requirement of the grounded approach new

questions were added to carry on with the demand of each in-depth interviewing process. Interpreter was used for interviewing person with hearing & speech disability. During the interviews researcher also wrote memo and observed participants.

All Interviews were recorded with digital voice recorder. Recording was done to facilitate the flow of the conversation and preventing disruption. It was also helpful in ensuring the accuracy of transcription. Each participant was interviewed for approximately 30 to 90 minutes. The recorded interviews were stored in a personal computer for transcription.

2.7 Data analysis procedure

In grounded theory approach data was analyzed in detailed procedure. Data analysis began with first interview. In this research data were analyzed parallel with data collection procedure. The emerging concept from the analysis was used in later data collection. The whole data collection process was guided by theoretical sampling and in-depth interviews continued until the data were saturated. At the beginning, recorded data was transformed verbatim in textual form. Two phases of coding was done on transcribed data using Nvivo-10 software. These steps of analyzing data are described in the following sections.

2.7.1 Data transcription. All interviews were recorded as audio form. Then this data were manually typed into textual form using Microsoft word. All identification information was removed during data transcription process. All transcripts were assigned with a unique code to de-identify the data. Some of the transcripts were written by paid transcriber to reduce the work load of the researcher. In such cases, the researcher thoroughly checked the whole transcript for error by simultaneously reading the typed transcripts and listening to the audio records. The finalized transcripts were imported into NVivo-10 project file.

2.7.2 Memo writing. During interview, researcher wrote her observation and insights about the participants and the topic into memo. It was helpful in building impression and hypothesis regarding the phenomena under study. Memos were also written during coding. These memos are analytical ideas of the researchers and serve as guides in the development and revision of the codes and categories (Corbin & Strauss, 2008). These memos served as the theoretical notes about the data and identify the conceptual connections between categories (Corbin & Strauss, 2008).

2.7.3 Use Nvivo-10 software. NVivo- 10, a computer based software program that was used for aiding the analysis of qualitative data. This software was helpful in coding sections from different contexts and then bringing together the codes from same or different transcript to allow carrying out comparison among them seamlessly.

2.7.4 Data coding. It was the most important part of data analysis because coding help the researcher building connection among discrete data elements. Grounded theory provides a procedure for developing theory through, categorizing of information (open coding), interconnecting the categories (axial coding), and building a “story” that connects the categories (selective coding) which finally ends with a discursive set of theoretical propositions (Strauss & Corbin, 1990).

Open coding. The first step of analysis is open coding. In the open coding phase, researcher went through all the transcripts line by line to identify significant statement and content. These contents were then put into a self explanatory code. Exhaustive coding of the complete transcripts was achieved through repeated rereading of the transcripts. During this

process of the open codes were revised, merged and renamed several times until they were convincingly placed under the axial categories.

Axial coding. Axial coding is the phase where concepts and categories are refined and relationships among them are pursued systematically. It was the second stage of coding. In this step researcher looked for common theme and central phenomena that were essential to the experience within and between the participants. These connections were further explored and analyzed between categories. Axial coding was performed after substantial amount of open coding were done. When researcher determine that coding has lead them to see the emergence of a model then in the final step researcher organized all the categories into the figural form of a model. That figure described all the process under the research phenomena. In this research researcher formation the broad categories and made a diagram of mental model of people with disability.

CHAPTER 3

FINDINGS

The findings of this study are presented in detailed narrative along with tabular and figural representation. To identify the nature and development of mental health problems among persons with disabilities, the transcripts were reviewed several times.

The analysis of data started while the interviews were still going on. The content analyses were done using the procedures suggested by Corbin and Strauss (2008) that involve open coding and axial coding. The themes generated through the content analyses were organized into meaningful categories and the connections between them were derived conceptually in line with the patterns suggested by the data collected.

The coding revealed several categories and sub-categories of themes. Similar categories were grouped under broader categories. By analyzing the data from people with disabilities, 6 themes and 45 categories were found from the initial coding and they are presented in the following table (3.1.).

Table 3.1.

Table of Themes and Categories

Themes	Categories
Family view	<ul style="list-style-type: none"> • Seeing as burden • Being non-supportive • Perceiving as insignificant
Social view	<ul style="list-style-type: none"> • Disrespecting • Labeling • Careless dealing • Avoiding • Blaming • Jealous attitude • Stigmatizing • Victimizing
Self view	<ul style="list-style-type: none"> • Deprived • Devalued • Imprisoned • Segregated • Stigmatized
Real life aspects	<ul style="list-style-type: none"> • Bindings • Lack of resources • Communication difficulties • Ignorance of government

<p>Mental health problems</p>	<ul style="list-style-type: none"> • Helplessness • Feeling of incapability • Feeling of being a burden • Uselessness • Feeling neglected • Feeling discriminated • Feeling disrespected • Sadness • Numbness • Embarrassment • Fear of abuse • Feeling offended • Support less • Feeling uncertain • Pain • Thoughts of suicide • Thoughts of incapability • Thoughts of inferiority • Erratic behavior • Avoidance • Abusing drugs
<p>Conception of disability</p>	<ul style="list-style-type: none"> • Dependent • Incapable • Inanimate • Discriminated

The table gives an overview of the people with disabilities, the views of the family and the society about them, their own views about themselves, and their perceived conceptions of

their mental health problems or disabilities. Discussions on the subcategories in association with the categories are given below.

3.1 Family view.

This research indicates that the family has a role of influence on the life of a person with disability. The behavior and perceptions of family members guide their feelings and perceptions. The family's view about people with disabilities can be further categorized into three sections, which are discussed below.

3.1.1 Seeing as burden. The participants reported that their families viewed them as a burden, as most of them were unemployed and unable to contribute to their families. Moreover, as disable people, they needed extra care and support from other members of the family and the family members provided that with annoyance and reluctance. This also created a feeling of being a burden in them. Two of the quotations that reflect this feeling of the participants are given below.

"My wife told me offensively – Okay, sit, eat, and do nothing. That is what you are good at." [Male, visual disability]

"Yes, they (brother and sister in laws) felt that. They are not like my mother who would say, this is my child, not a burden to me. Yes, I am a burden to them." [Female, visual disability]

3.1.2 Being non-supportive. According to their reports, the participants with disabilities did not get the proper support from the family. They have to face discrimination from the family when it comes to getting financial or logistic supports.

The rest of the family members always get more privilege than them. One of the participants said when they don't get support from the family, how could they expect support from other places?

“When our families do not support us, how is it possible for other organizations or institutions to support us?” [Male, hearing and speech disability]

Some other participants said:

“Care should come from the family first. Yet, the family members don't take the proper care of these people with disabilities...” [Male, visual disability]

3.1.3 Perceiving as insignificant. People with disabilities don't get importance in their families. As family members, they don't have the opportunity to give an opinion. One of the participants said, since he became a disabled, he has not been treated the way the elder son of a family usually is. Here are some examples of such situations:

“The family always denies me any importance. They say, ‘he is useless; so keep him away from this matter.’” [Male, visual disability]

“As no one calls me to discuss any family matter, I feel very sad...” [Male, physical disability]

These quotations indicate that the families don't value them properly and try to avoid them.

3.2 Social view.

One of the main themes is social view. In this section people with disabilities reveal how the society thinks, views or perceives them. There are eight categories on this theme. All

the categories reveal some major negative views of the society towards people with disabilities. The categories are discussed below.

3.2.1 Disrespecting. From the conversations of the participants it is clear that the people around people with disabilities do not respect them. They face disregard and insult from everywhere. People use harsh language to these people with disabilities. They degrade them with their speeches and activities. One of the participants reported that some people insulted him by using some derogatory terms about disability, for example,

"They said, the 'langra' (a very derogatory term for a person with physical disability) did this or the 'langra' did that. They could say that as I am a disabled." [Male, physical disability]

Some participants said people sympathize with them, but do not respect them properly when the need arises. One of the participants said,

"They do not want to respect. It is not only my opinion, if you ask the people of the society, they too will say that they have sympathy for us, but they don't believe in equal rights." [Female, physical disability]

3.2.2 Labeling. The participants reported that the society always label them. There is a tendency to view the people with disabilities as a different category. The society tries to isolate them in a category and judges them. As for example,

"Society never forgets to remind me that I am blind." [Male, visual disability]

Even some participants reported that this labeling is responsible for discriminative behavior.

"...this discrimination happens with the disable people, because they (the society) think that the disabled are weak and incapable." [Male, visual disability]

3.2.3 Careless dealing. Normal people are careless about people with disabilities. They do not care about what they say or how they feel. For example,

"But I never found anyone who would listen to me. They do not even bother about me." [Male, hearing and speech disability]

"It has happened many times. I asked someone about where he was going. He replied that he was going to bring something from Kana's house or Langra's house (kana and langra are very derogatory terms for person with physically disability). He said right in front of me, as if it means nothing. He didn't even think about how I would feel about this. He said it to someone else, but still it did hurt me." [Male, Physical disability]

From the stance of such careless dealing, the society generally does not want to take any kind of responsibility and is not supportive of the needs or inclined to do any work for the people with disabilities. Some of the participants reported that:

"When I was a child, I begged them to change the arrangement of the classroom, but the authorities didn't pay any attention. The change of arrangement would raise the expenses a little. That's why they didn't do it. The schools were never interested in this. The problem is the same everywhere." [Male, hearing and speech disability]

"The attitude of the people of our society is always self-centered. They have no time to spend on other people's problems." [Male, visual disability]

3.2.4 Avoiding. This research shows that people have a common tendency to avoid people with disabilities. Sometimes they feel embarrassed or extra-burdened for which they avoid them. There are some examples,

"My husband never feels comfortable to introduce me as his wife; he tries to avoid it when he is in some parties or any social gatherings. He is at ease to introduce his mother, sister or sister-in-law. But, when I urge him to introduce me, I see him hesitate. Then I know my eye problem is the reason for his hesitation." [Female, visual disability]

"I was clearly seeing that he had been avoiding me. I realized that he had some negative thoughts about me. That's why he avoided me." [Male, visual disability]

3.2.5 Blaming. The society sometimes blames them only because they were people with disabilities. They were blamed for their disabilities and sometimes for their incapability. One of the participants reported that the people around her used to use offensive language about her disability and marriage.

"People never forget to remind me, 'You are blind. Who will marry you? What will you do? You can't manage the household work. Who will take you and give you food without having any work in exchange?' [Female, visual disability]

Another participant said when she was abused by someone; the society did not stand for her and blamed her for it.

"I was tortured, and I told this to my parents and other people. When I went to the community leaders for justice, they blamed me instead." [Female, hearing and speech disability]

"The society threw some more blames at me. That's because I was a deaf woman." [Female, hearing and speech disability]

3.2.6 Jealous attitude. In our society it is hard for people with disabilities to do something. But, they try and sometimes they are successful. Surprisingly, our society can't take it easily. Some of the participants reported that they saw jealousy. They reported,

"Some neighbors and cousins sometimes muttered, out of jealousy, 'he got so many things despite being a disabled.' Their financial condition was not well. They said nothing in front of me. But they talked behind my back all the time." [Male, physical disability]

"She is a disabled. Why is she in such a nice place? She deserves a dirty place. She should remain in dirt, but she blooms like a flower!" [Female, physical disability]

In the second quote, the female participant was describing how her neighbors reacted when she tried to do some work and live a better life.

3.2.7 Stigmatizing. While sharing her experience about marriage proposals, one of the participants pointed out the numerous wrong concepts and stigmas prevalent in the society about marrying a person with disability.

"The society holds this superstition that if someone marries a disabled person, their offspring will be disabled by birth." [Female, physical disability]

3.2.8 Victimizing. The participants reported that many times in their life, their rights were violated and they were victimized. They were tortured by many people who merely hated them and people who wanted to get advantages from them. One participant said a boy in her village tried to rape her, because she was blind and might not recognize him. Here are two of their statements,

"I was tortured. Only because I was deaf, I was victimized." [Female, hearing and speech disability]

"They always seek advantages. Everyone wants to take advantages. There are not many good people in the society." [Female, physical disability]

From the above discussion, it is clear that the family view and the social view affect people with disabilities which also form their self view. The interconnection between the themes is presented in the following figure (3.1.).

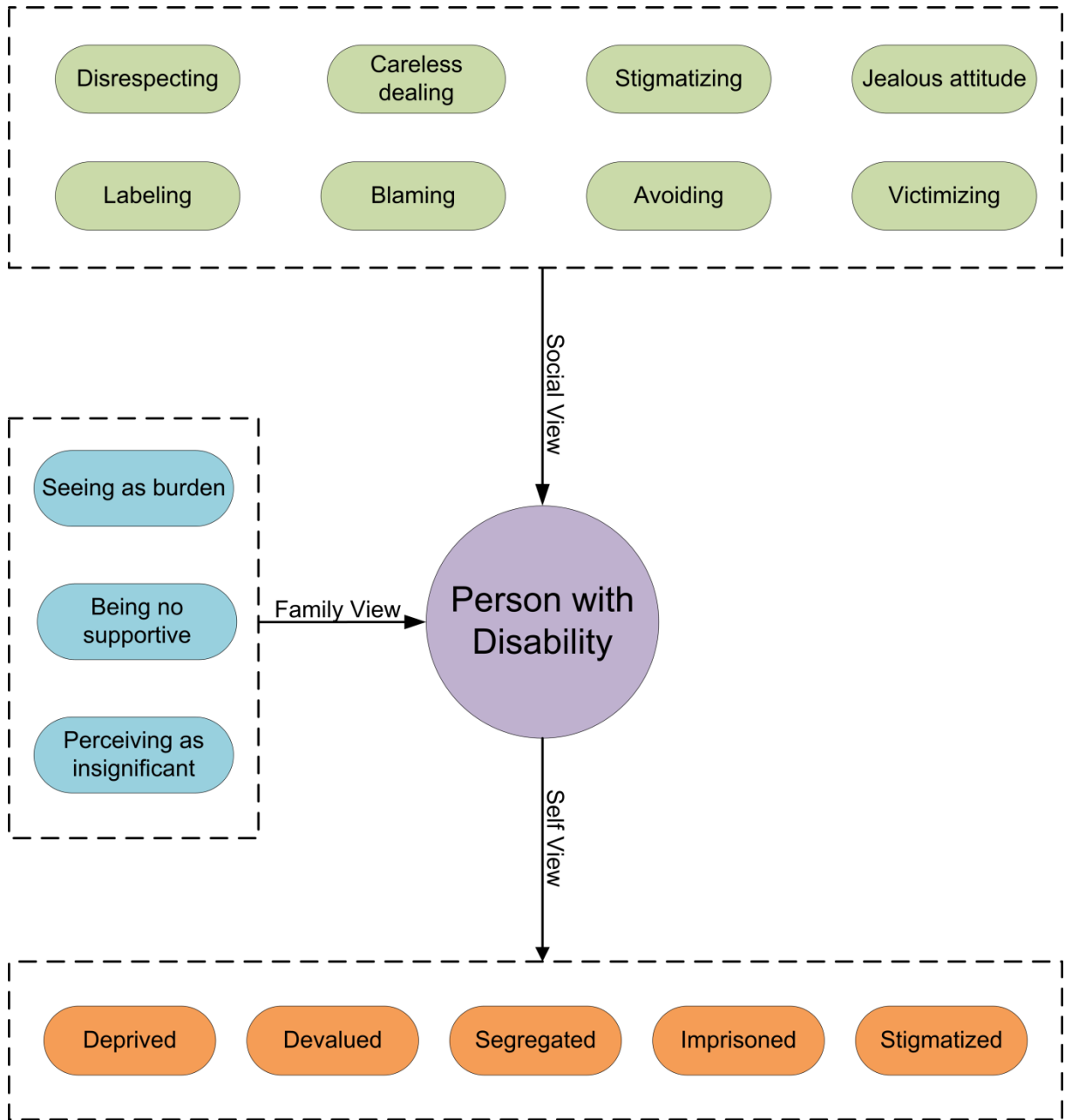


Figure 3.1. Effects of family view and social view on people with disabilities

3.3 Self view.

During the interviews, the participants shared how they felt or viewed about themselves. How they view themselves is largely dependent on how the family or the society views them and treats them. Self-view is the reflection of others' views and attitudes towards them. There are five sub-categories under this category. They are discussed below.

3.3.1 Deprived. Persons with disabilities view themselves as deprived. They do not have their rights. They never get the facilities they deserve. They are neglected by the family and the society. The society is careless about them. They are deprived as human beings. Sharing her pains of being deprived, a female participant said, as she was the elder sister, she should have been married off before her little sister. But no good marriage proposal came for her because of her disability and she had to approve her sister's marriage prior to her own. It was a painful experience as reflected in the following statement.

"I still feel that psychological pain. I have a sister. Although she was younger, she got married and is now a mother. She is living happily with her husband and I am left alone only to bless her."[Female, physical disability]

3.3.2 Devalued. With all such negative emotions and incapability, people with disabilities start to feel that their lives are of no value. They are insignificant in the family. They are avoided by the society; sometimes they are even blamed for their disabilities. Growing up in such a harsh environment is intolerable and they end up coming to the conviction that their lives are meaningless. They find no purpose of life. There is no

achievement, no good things, and not even a positive event in their life. The following two quotes reflect such feelings,

"Sometimes I thought why I should live; there was no reason for that." [Male, physical disability]

"Then I thought why did Allah create me?" [Male, visual disability]

The second quotation expresses a strong negative feeling. The person was so fed up with his life that he even questioned the purpose of God for creating him with disability.

3.3.3 Imprisoned. The participant said sometimes it seemed as if they were in prison. This feeling comes from their limitation of movement and communication and the lack of supportive facilities. They do not have enough facility to move around freely. When they try to do something, they are faced with barriers. It feels same as imprisonment. A participant expressed this feeling thus,

"...a person with physical disability cannot even imagine going anywhere alone. He feels bound. It feels like being trapped in a net. Like imprisonment! For example, I too feel the same." [Male, physical disability]

3.3.4 Segregated. The participants said they are segregated from the society or other people. They see themselves as different from others, because the society avoids them. They face insult from the society; and sometimes they have to stay alone, because their family members feel they are not fit to go to a party or any sort of gathering. One of the participants said,

"The truth is the society is for the normal people, not for us. There is no such thing as how we view each other, because, there is no communication between us. We are alien to the mainstream society. They do not understand us." [Female, hearing and speech disability]

"I felt a lot of pain in my childhood, as I thought I alone was deaf and everyone else could talk except me." [Female, hearing and speech disability]

3.3.5 Stigmatized. A person with disability is also a part of the society, just like other people. He or she learns from the family and the society. When the society holds stigmatized views about disabilities, people with disabilities also start acquiring some stigmatized views about themselves. They think the ways they are treated by the society are quite normal. So, they too are not much open-minded about other people with disabilities. One of the participants said she did not want to marry a person with disability because of her stigmatized opinion.

"If I marry a disabled person, our offspring will be disabled hereditarily. I am a disabled person. I could not balance myself. Then how would our offspring manage things?" [Female, physical disability]

3.4 Real life aspects.

People with disabilities suffer numerous restrictions in their life. They said they had to face many restriction; they became very poor, had no facilities or resources, and had to depend on others to do everyday works. Some real-life crises plagued their life to which they had no solution and their communication incapability only made things worse. These problems restricted them in every aspect of life.

3.4.1 Bindings. Bindings are the most crucial obstacles for people with disabilities. They have bindings to move, to perform services, to enjoy in a word, to do almost everything. They face challenges in doing anything. There are so many difficulties and so many restrictions on them that they often get disheartened and stop pursuing their dreams. One of the participants said,

"If you wish to eat something, you could do any job and earn some money and then you could buy the food and eat it. If you fancy a cloth, you could go to the market and buy and wear it. But, we could do none of these." [Male, visual disability]

People with disabilities also have very little opportunity of getting extra care and facilities, as the hospitals and banks in this country do not have enough special policies for the disabled. There are also limited facilities for the disabled in the country's transport system and other sectors. This deficiency of facilities deters many disabled persons from visiting places of necessity as well as of recreation. A participant said,

"I have not gone outside for many years now due to the lack of toilet facility. Who would take me out? If I go somewhere and need a toilet, won't it be a problem? That's why I don't go anywhere." [Male, physical disability]

3.4.2 Lack of resources. The participants said there is a lack of facilities or resources in our country for them. Governmental and nongovernmental organizations too have little fund for them, as they are not interested in promoting the welfare of this group of people. There is no job opportunity or source of earning for them. A volunteer who worked in a society for the disabled said,

"Previously, there was no educational arrangement for the deaf people in Bangladesh. Do you know that now there are only seven schools in Bangladesh for the deaf? These schools have the facilities to educate students up to Class Eight only. In the past, it was only up to Class Five. This program started probably 5-6 years ago." [Female, hearing and speech disability]

Some NGOs do work for the people with disabilities. Although their number is not insignificant, they are prone to rivalry with one another. Such real-life problems restrict the development of the people with disabilities. One of the statements indicates the problem,

"In our country, there are some conflicts between the NGOs. One NGO doesn't like another. Their inter-conflicts make the job more difficult. This is quite upsetting." [Male, hearing and speech disability]

3.4.3 Communication difficulties. A person with hearing and speech disability mainly suffers from inter-personal communication problems. Only a few people can understand them. It is very difficult for them to communicate with the common people. This is a major restriction of their life. One participant reported,

"I can't communicate, which is very painful. I can't share my opinions. I have many issues to share. I have so many problems that I can't even share with my husband. When I have some gynecological problems, I feel very helpless and find no one to describe the exact problem." [Female, hearing and speech disability]

3.4.4 Ignorance of government. Some of the participants reported that when they tried to communicate with the government to seek help, they noticed that the government does

not take enough initiatives for the people with disabilities. One of the statements on this topic was,

"We did some great work. Those were also discussed in the ministry. They knew that we worked for establishing the disabled people's rights. But the outcome is zero. They filed our document and put it on ice. As a result, we had to suspend our program. This is one of our major obstacles." [Male, hearing and speech disability]

3.5 Mental health problems.

When we say that a person suffers from mental health problems, we mean there are a significant level of disturbances in that individual's cognition, emotion regulation and behavior. Mental health problems are associated with social and personal factors. This study found that when the family and the society perceive and treat a people with disability negatively, a negative self-view may arise in them. This negative self-view, coupled with real-life problems, contribute towards the development of mental health problems among the persons with disabilities. The three main areas, emotional, cognitive and behavioral aspects of mental health problems among the people with disabilities are given below.

3.5.1 Emotional aspects. The people with mental disabilities have lots of negative emotions. These negative emotions come from the way they are perceived by their families or the society. When they are discriminated against and deprived by others, they feel negative emotions. They also feel such emotions when they realize that they are incapable and are a burden to others. Some of these negative emotions were reported by the participants.

Helplessness. Most of the participants reported that they felt helpless. They felt helpless when they tried to do something or to move around. They also felt helpless when

they realized that they had no earning sources and they were dependent on other people or family members. They felt helpless when they wanted their rights and the society refused to give them. Their limitations also made them feel helpless. Some of their statements expressing this helplessness are quoted here.

"I have no one. Where should I go? So much pain! My life has been a continuum of such pain. I have grown up bearing this pain." [Female, visual disability]

"I will need these things as long as I live. Who will provide these? Who will bear the cost? How will I earn? I have no land to work on. I don't have anything. I am poor." [Male, visual disability]

Feeling of incapability. The people with disabilities said they feel incapable. They cannot do anything properly without the help of others, and some of them even cannot move, making them feel incapable. One of the statements expressing this feeling of being incapable is given below.

"Then I feel incapable. I have some limitation. My limitation reminds me of my incapability." [Male, physical disability]

Feeling of being a burden. The participants said they feel they are a burden for others due to their disabilities. Most of the times they need help to move or to carry something. They also are dependent on their families for their expenses. These things create this feeling in them. Two of the participants narrated the feeling thus.

"Suppose I have to attend a program. I want to go and it is really necessary for me to go. But my presence could make trouble for others. So I can't go." [Male, physical disability]

"Yes, if I go somewhere I need two persons to carry me. That means whenever I want to do a job, I have to engage more people." [Male, physical disability]

Uselessness. This is the most common feeling of the people with disabilities. These people have been ill-treated by the society throughout their life. This is the reason why they always feel that they are out of place. One of the participants said,

"We don't have any value. The disable people are just like old cloths." [Male, visual disability]

They think they are not suitable for any kind of work or social activity. The society also provokes them to accept the idea that they are valueless.

Feeling neglected. Most of the participants felt that they were neglected by the family and the society. They did not have any right to opinion and respect. They were neglected because they did not contribute financially to their families and needed help for every work. Sometimes, when they needed help, they (family members or other people) did not offer it because they thought it was a waste of time. Here is an exemplary statement.

"...they used to say that they (family members or other people) did not have time, they were in a hurry. I should come later." [Male, physical disability]

Feeling discriminated. Discrimination was the most common problem the participants face. They feel discriminated against everywhere. This emotion had become more and

stronger as they grew up. They were discriminated by their siblings and neighbors, by their community and even by the government. Equal rights and equity just do not exist for them. Here is relevant statement made by a participant,

“There is nothing more to say. There was a cowshed beside my room. I had to live there.” [Male, physical disability]

Feeling disrespected. The people with disabilities feel disrespected as a person or a human being. They have reported that the people around them show no respect towards them. One of the participants said her husband also disrespects her. Her statement was,

“It was very painful for me when I heard my husband referring to me as ‘that lady’. It was only because I was blind.” [Female, visual disability]

Sadness. All of the participants said they feel sad. Sometimes they feel sad for their disabilities. One of the participants said,

“It was really sad for me that I could see through only one eye.” [Female, visual disability]

They also felt sad for the humiliation, disrespect, negligence, and discrimination they receive from the society. Their incapability to lead a life like a normal person also makes them sad. The rude attitudes of the people close to them also add to their sadness.

Numbness. Sometimes the people with disabilities feel numb. They suffer lifelong for their disabilities and grow up in such a society that is not sympathetic to them. To avoid this enormous pain and pressure, they start becoming defensive and this is the main reason for their numbness. One participant said,

"But now there are no tears in my eyes. After bearing so much pain, my eyes have dried out. I feel nothing now." [Male, physical disability]

Embarrassment. The participants said they feel embarrassed when they seek help from others. They also feel embarrassed about their looks and physical limitations. For example,

"Yes, he had accepted me as his wife, but he felt embarrassed to introduce me to others as his wife. So I rarely went outside with him." [Female, visual disability]

"While sitting with some friend in a place, I had to remain sitting although I felt the urge to go to toilet. When everyone had left, I requested someone to take me home. It was very embarrassing." [Male, physical disability]

Fear of abuse. The participants reported that they have a fear of abuse. They think people want to get advantages from them for their weakness. They have the fear because they cannot protect themselves. One of the participants said,

"I am afraid that someone could touch me intentionally on road. If they touch me, I have nothing to do. I am afraid of being abused. I feel panic." [Female, physical disability]

Feeling offended. That is one of the feelings the people with disabilities have. They feel offended when they realize that some people who act very friendly with them and say negative things about them to other people. One participant said,

"...If I met that person again, I would feel bad. I thought we were on a good term. How could he tell those things about me? If he had problems, why didn't he tell me directly?" [Male, physical disability]

Support less. Although the disabled people need more support to lead a sound life, they often get less support than the normal people. The support they receive from their families, the society, their community and the government is not enough. Most of them are denied schooling and other basic human rights. The surroundings are not supportive of them to live. One participant said,

"As a person with speech and hearing disability, my main pain is that I never get the proper support from anywhere. It is painful." [Female, hearing and speech disability]

Feeling uncertain. Most of the participants reported that they are worried about their future. The future is always worse for them. They fear about their life when they have to stay alone. One of the statements reflects this tension.

"My future would be worse. Although now I am fine but my future would be worse." [Female, physical disability]

Pain. Pain is the core emotion or feeling of the people with disabilities. They feel pain for their disabilities and also for the behavior or the attitude of others towards them. They suffer huge mental pain, sometimes even physical pain. They have no hope that this pain would reduce. One participant said,

"Yes, life is painful. Whatever you try to make it easy, the pain remains. It comes periodically." [Female, physical disability]

The people with disabilities suffer from many types of restrictions and all of these are painful. Some of them cannot hear, some of them cannot see. Some of them cannot move. This is very painful for them. One of them said,

"There are lots of people. All of them can move, but I am stuck in one place. Everything else is fine, I can understand, I can talk, but I can't travel." [Male, physical disability]

They also experience the pain of rejection. They are subjected to rejection in many areas such as finding a job and matrimony. It is painful for them. Whenever they remember such an event, the pain returns. One of the participants said,

"When his daughter grows up I would tell him that he had neglected me. So Allah gave him a disabled daughter. When his daughter would remain unmarried then he would understand how painful it is for a father to have an unmarried daughter." [Female, physical disability]

Disability itself can be painful. The people with physical disabilities may have some biological pain. A participant said:

"Naturally a person feels pain if he can't walk. If any part of the body gets impaired, it becomes very painful for him. For example, suddenly your leg get impaired, you would feel devastated." [Female, physical disability]

The pain is almost incurable or unchangeable. So, the pain continues as long as they live.

3.5.2 Cognitive aspects. Cognition is a mental process of acquiring knowledge and understanding through thinking, experience and the senses. When the people with disabilities experience a negative situation, they also experience a negative feeling. It also creates a negative cognition. The common negative cognitions prevalent among the people with disabilities are given below.

Thought of suicide. Some of the participants have reported that they have had suicidal thoughts. When they feel that they are different from others or they are a burden for someone, they do not want to live. They think death is the only peace they can get. The following two statements depict this thought process.

"Sometimes I even thought what the point of living is. Everyone can talk. It's only me who can't talk." [Female, hearing and speech disability]

"At night I hit at my leg myself. I beat myself as hard as I could. I thought to myself - why should I live? What would be the purpose of my life? I have to always wait for someone's help. I have to do toilet in bed. How long people will tolerate me? Would I be scolded by them every day? So what is the purpose of my life...?" [Male, physical disability]

They had thoughts and sometimes they had suicidal ideation. Some of them made one or two attempts at suicide. These thoughts came from frustration, the feeling of being a burden, etc.

Thought of incapability. The people with disabilities have the thought of incapability. This thought came from some real-life aspects like bindings, communication problems etc. When they face the bindings of movements, bindings of communications, bindings of

working, then they feel helpless and incapable and fail to think like a rational person. One of the related statements was,

“Helpless...cannot see. As I cannot do my work so I feel helpless. It’s a great helpless feeling.” [Male, visual disability]

They also have a feeling of self-loathing as they have to depend on others and cannot live an independent life.

Thought of inferiority. When the people with disabilities are deprived by the family and the society, it triggers a thought of inferiority in them. For example, one of the participants reported that.

“Then I thought, if I could see, I might have had a better opportunity for marriage or maintaining a better social life. I would not be so dependent on others. I felt inferior.” [Female, visual disability]

This inferiority complex makes their life more difficult. They become more introvert. They get less enthusiastic to cooperate and lead a life of vicious cycle of loneliness. Their standard of living starts to fall. They start becoming outsiders. They are destined for their lack of responsibilities. They think of themselves as the lowest grade of people. One statement on the issue was this,

“I have a feeling that if I’m abused or something, then I would not get justice. The community thinks of me as a burden. They would never prioritize my problems over any influential person.” [Female, hearing and speech disability]

3.5.3 Behavioral aspects. When a person with disability possesses some negative emotions and cognitions, it eventually affects his behavior. Then he/she may show some unusual behavior. The participants reported that they had some behavioral problems like,

Erratic behavior. They show some erratic behaviors. One of the participants said:

“Yes, then I did not want to share anything with anyone. Then my mood was irritable and if anyone came to talk to me, I became angry. I did not speak.” [Female, hearing and speech disability]

Avoidance. When the people with disabilities feel negative emotions, it becomes tougher for them to socialize. One of the participants said,

“For that reason I did not go anywhere.” [Female, physical disability]

Another participant said when she was upset she would do this,

“I stayed quiet, fell asleep, and did not take food. Did not go anywhere and did not communicate with others. Day after day I passed just sleeping.” [Female, hearing and speech disability]

Abusing drugs. There were also some problems of drug abuse among the people with disabilities. One of the participants said sometime he could not tolerate the physical pain and took some drugs.

3.6 Conception of Disability.

Disability is a term that is conceived through the interaction of the society, the family, the person and the phenomenon of disability itself. This process starts from the disabling

incident but continues to evolve. Some social and family aspects also play a role in the making of the self-view of a disabled person. There are some real-life aspects, too, such as restrictions and boundaries. This self-view and the real-life aspects give rise to the psychological problems. And finally, all these factors make up the conception of disability.

The conception of disability expresses how the family, the society and a person with disability view or perceive disability. That means when we use the term disability, these conceptions pop up in our mind. There are mainly four things we think about a person with disability. They are discussed below.

3.6.1 Dependent. Our first perception about the people with disabilities is that they are dependent. The people with disabilities are dependent for their movement and other work. Most of them do not earn a living and are dependent on their families or other people. One of them reported,

“When I went to somewhere I could not walk alone. I had to walk with the support of something. For example, I could not carry books to school. My classmates carry those for me.” [Female, physical disability]

That means they need other people’s support in their daily life. They are also dependent for their basic needs on others. Another participant said:

“That was a great sad story. I had to eat what my father provided for me.” [Male, physical disability]

3.6.2 Incapable. The second perception is that they are incapable. The people with disabilities have some sort of incapability. They may be skillful in some way but they have some limitations too. That makes them feel incapable. One of the participants reported,

“When a simple task needs only ten minutes to do for others, I need an hour. I have to pay for finishing simple tasks that I could do easily if I were a normal person. It is sad when you know how simply a work can be done, but only you are not fit for that task.”
[Male, physical disability]

They also feel incapable because they cannot help others like a normal person or contribute anyway to the family.

3.6.3 Inanimate. The third perception is that a person with disability feels that they are inanimate. When a person with disability cannot move, cannot do anything important and even cannot communicate, he thinks he is inanimate. The people with disabilities have compared themselves with stone, cow and slow animals like turtle. One of the participants said,

“I also started to think that I could not do anything. I am inanimate. My life is no better than a cow.” *[Female, hearing and speech disability]*

3.6.4 Discriminated. The fourth perception is the people with disabilities are discriminated against. The participants reported that they were discriminated against by the society. There is no place for them where they could enjoy equal rights. Although some social awareness is raised to create a society free of discrimination for the disabled, people largely remain ignorant about the fact and do nothing to ensure the rights of the disabled people. Some statements indicated this issue:

“When I was at the examination hall, I had been provided with the same time as other students. I couldn’t finish the answers. If they gave me some extra time, I would have finished the answers.” [Male, visual disability]

“I need a job badly, but when I went for interviews, they did not select me only because of my vision problem. They made excuses like ‘You have to work on computer. You are not fit for this job’” [Female, visual disability]

They even get discriminated against by their parents. A participant said,

“Everything is the same, we are two girls from the same family, but we are different and treated differently.” [Female, physical disability]

3.7 Model building

Finally, a model was built that describes the inter-relationship between the themes. Analyzing all the data, categories and themes, the present researcher has conceptualized the model on the development of mental health problems. Figure 3.2 shows how the mental health problems develop in the people with disabilities and how the conceptions are created and how do they influence the process.

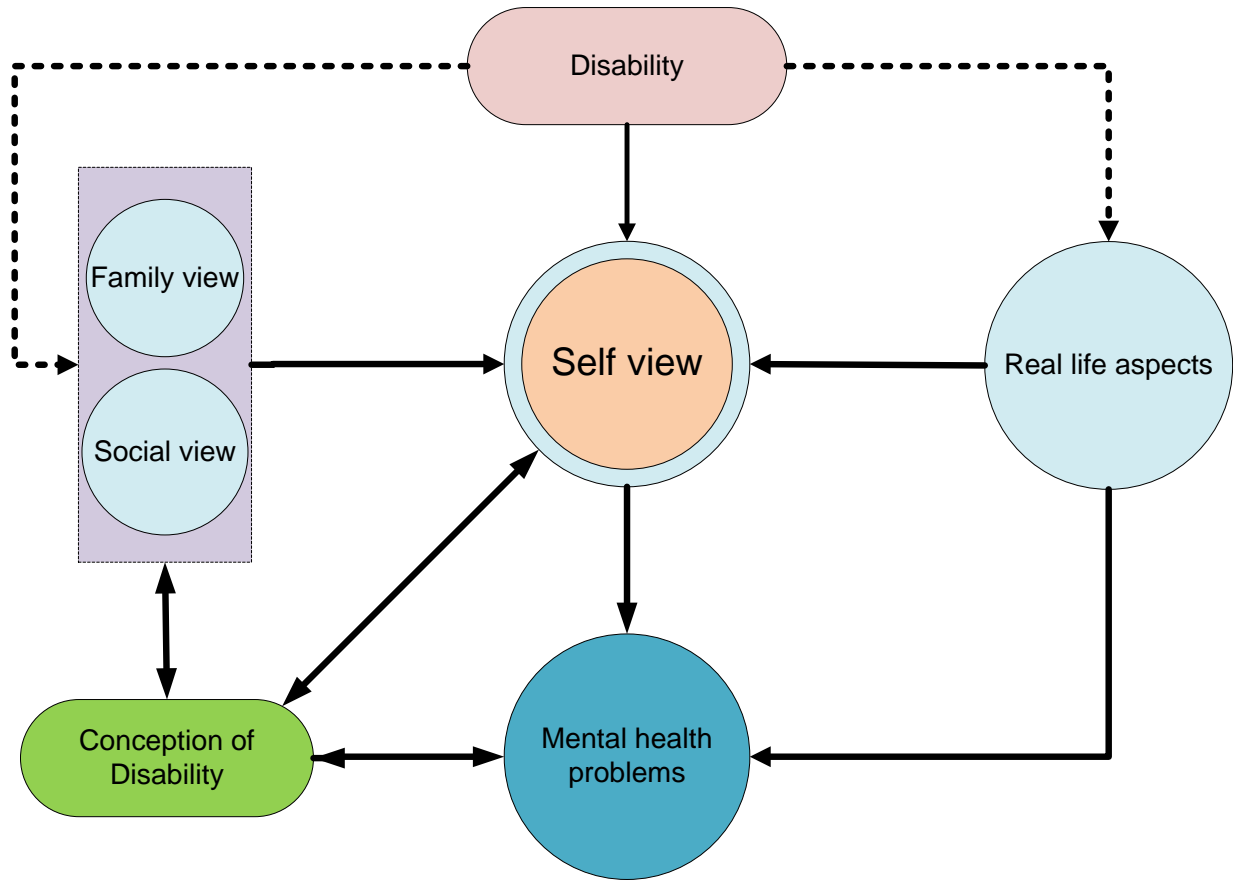


Figure 3.2. The proposed model on development of mental health problems in the people with disabilities

The model demonstrates how mental health problems developed and how the conception of disability is created. At first, the disability occurs. Then the views of the family and the society about a person with disability are formed. After that, the self-perception is created through family and social views, which has been indicated by the connecting arrows. There are some contributions, too, of the disability and real-life aspects indicated by the dotted arrows. This negative self-view and real-life aspect give rise to mental health problems in the people with disabilities. Finally, the disability conception is created by the views of the family, the society and the self as well as mental health problems and real-life aspects. The

conception of disability, in its turn, also contributes to the formation of the family, societal and self views.

Disability itself is a neutral condition, whether it occurs by accident or by birth. But a person with disability has to live through various types of negative experiences when he/she grows up in a family and a society. The research findings supports that he/she may not get appropriate attention and importance from the family and become neglected. Sometimes he/she becomes a burden for the family. Moreover, the person gets various negative impressions from the society. At the initial stage, a person with disability is labeled in a different category and does not get the appropriate respect. In most cases, the society is guided by stereotyped set of beliefs. To get rid of the extra-responsibilities, sometimes the society becomes careless to them and, at the same time, tries to avoid them. Again, sometimes the society unduly condemns a person with disability. Even if a person with disability attains a good position in life through his/her own effort, the society may not accept it warmly. Members of the society often get jealous. There are some stigmas in the society about the people with disabilities. The study findings indicate that these things are the contributing factors for not choosing a person with disability as a wife or husband. The people with disabilities are sometimes victimized by the society or family members, who often try to take advantages of a person with disability. The people with disabilities can rarely exercise their rights.

The study findings suggest that when a person go through these negative experiences/situations, his/her self-view also undergoes changes or are influenced by the situations. The people with disabilities view themselves as deprived. Because, most of the times, they do not get proper respect. Most of the people around them are careless about their matters and

sometimes the people with disabilities are victimized. The people with disabilities also view themselves as imprisoned, because, as the participants have reported, due to their disabilities their movements and communication become limited. They feel they are living in a locked place. They also think their life has become valueless and meaningless.

There is also a factor named ‘real-life aspect’ that contributes towards the creation of negative self-perception in a person with disability. The people with disabilities always have some bindings and they also get fewer facilities than the normal people. For example, when a person with disability tries to do something, in most cases, he/she does not get help from anywhere. In this study participant reported that the governmental and nongovernmental organizations have little interest in improving things for the people with disabilities. This is indicated that negative feelings can be generated through this situation. So, the negative self-view in a person with disability is evolved with the influence of the family, society and real-life aspects. And this negative self-view contribute to develop mental health problems in them.

Now, how does the conception of disability evolve? According to this study conception of disability means how the members of the society and the family and the people with disabilities view disability. All of them perceive disability by this concept. This conception is vice versa. The family view, social view, self-view and mental health problems make the conception and the conception of disability also help in their creation. This conception has four main perceptions about a person with disability. These are dependent, incapable, inanimate, and discriminated. The findings indicate that most of the people view a person with disability as a dependent. By this view they mean that a person with disability is dependent for his/her movements and living expenses. By the perception of ‘incapable’

people view a person with disability does not have the capability to do anything. They also view the people with disabilities as inanimate, as if they were not living beings. Finally, they view the people with disabilities as discriminated. Circularly, these four core perceptions contribute towards the development of the family, social and self views.

CHAPTER 4

DISCUSSION AND CONCLUSION

The present study was designed to assess mental health problems in the people with disabilities. It has tried to understand the nature of psychological problems and explore the process underlining the development of psychological problems in the people with disabilities. The qualitative findings of the present study were presented in Chapter 3 and the results are discussed in this chapter.

4.1 Discussion

The people with disabilities have a greater risk of developing mental health problems than the general people. For example, in Australia 59% of the people with common mental disorders also have physical conditions (Australia, 2008). These mental health problems are sometimes diagnosable and sometimes only some symptoms are apparent. A research on physical disability and mental health revealed that there is a positive relationship between physical disability and the risk of cooccurring psychiatric disorders (Turner et al., 2006). A study by Lucas (2007) found that when a person becomes disabled, the stress suffered by that person increases significantly. Another study by Bruce (1999) found that physical disability was a risk factor for depression. The people with disabilities also have significantly more anxiety symptoms (Cardozo et al., 2004). Social anxiety disorder is more commonly found among the people with disabilities than other anxiety disorders. Prince et al. (2007) found that chronic diseases like disability can produce trauma, lifestyle changes, pain, stigma, loss of social support, distasteful treatment, and relationship breakdown.

The main findings of the study show how mental health problems developed in the people with disabilities. A disabled person has a poor psychological condition. Most of the

participants of this study were suffering from numerous emotional and behavioral problems which barred them from enjoying a quality life and created a large number of problems for them. One of the main contributory factors for mental health problems is the family's negative view. The attitude of the family members towards a person with disability is negative. Family members treat him/her as a burden and a less important member of the family, because a person with disability is unable to make financial contribution to the family. For that reason, the family members too don't want to invest in a person with disability. When a person with disability needs more support from the family, he/she actually receives less or no support. Sometimes, the family members or caregivers feel anxious about their illness. When family members perceive the people with disabilities as sick or disabled, they are 14 times more likely than others to seek treatment (GM Monawar Hosain & Chatterjee, 1998). Another study revealed that the impression of a caregiver is related with the quality of life of a person with disability (Alshubaili, Awadalla, Ohaeri, & Mabrouk, 2007). It is indicated that a caregiver's attitude or behavior affects a person with disability. Similarly, the present study has found that the negative impressions of family members contribute towards the development of mental health problems in the people with disabilities. Negative family views also have an impact on the societal issues.

Social support is often regarded as one of the most important factor in the life of a person with disability. Schulz and Decker (1985) revealed that the people with disabilities who had high levels of social support and were satisfied with their social contacts reported high levels of well-being. In this study, the participants said they receive poor social support which is related with their mental health problems. A person with disability is a part of the society, but the members of the society do not treat them as such. They treat the people with

disabilities as if they belong to another category. The members of the society label them and show disrespect. They often do not care for them. When a person with disability achieves something good, they may even become jealous. The society also holds stigmas about the people with disabilities. There are some undesirable effects of these stigmas on the life of a person with disability. These stigmas influence the conception of disability (Susman, 1994). A research by Albrecht and Devlieger (1999) revealed that the quality of life of a person with disability is dependent on the relationships within the person's social context and external environment. The current study found that when the family and social context and environment are negative, they have an impact on the mental health of a person with disability. Although these negative attitudes are perceived by the person with disability instead of observed or assessed afresh by the researcher from the members of their family or society, these findings are useful for understanding the psychological impact or experience of the individuals with disability.

These negative situations contribute towards the creation of negative self-views among the people with disabilities. They have a negative self-view of being deprived. Analyses have found that slight and non-supportive attitude of the family and also the labeling behavior of the society influence the process of generating the feeling of deprivation in a person with disability in a major way. The people with disabilities also feel that their life is meaningless and this feeling is associated with the society's carelessness and blaming behavior. Another strong self-view of the individuals with disabilities is that they are segregated from the rest of the society. This view is associated with the avoidance and labeling behavior on the part of the society and the family's non-supportive attitude. As a part of the society, they also share the same stigma. Along with these negative self-views, the

people with disabilities also view themselves as imprisoned, which was derived from their feelings of being a burden and incapacity.

The participants also reported some real-life aspects, which are true in our country. These aspects created some barriers in the lives of the people with disabilities. These barriers are lack of resources, problems in inter-personal communication, and negligence of governmental and non-governmental organizations. These factors are inter-connected and these connections contribute to the development of mental health problems in the people with disabilities. The study found three main aspects of mental health problems, i.e., emotional, cognitive and behavioral aspects. In the case of behavioral aspect, the researcher found that the people with disabilities sometimes abuse drugs to contain intense physical pain and also for entertainment or enjoyment. Some other researchers also have found similar behavior, that there is a positive relationship between physical disability and substance disorder, and that the risk is greater for men than for women, for the young than for the old (Turner & Noh, 1988)

Apart from mental health problems, a common pattern was observed in the study about the conception of disability. The members of the society have some common notions, a set of stereotyped beliefs, about disability. This set of beliefs promote negative self-views in the people with disabilities. On the other hand, a research done by Weinberg-Asher (1976) revealed that the persons with disabilities perceived themselves in the same way that the able-bodied persons perceived themselves. But the present study has found it to be different. It has found that the people with disabilities also have the same negative views as the family and the society have about them. The views of the people with disabilities about themselves are influenced by the negative views of the family and the society about them, while the poor support system the country offers them also contributes towards the negative feelings.

Another research found that participants who were disabled had significantly lower social functioning and poorer mental health status than those who were nondisabled. The people with disabilities have a significantly lower health perception (Cardozo et al., 2004) that is similar to this study.

Finally, a model was drawn based on the qualitative analyses of the data. The model explains the relationship between the categories as well as describes the process how mental health problems develop in the people with disabilities. This model also relates the conception of disability.

4.2 Implications of the study

This study finding is likely having multiple implications. It will be useful for the professionals in understanding the process of development of mental health problems in the people with disabilities. If we understand the process then we can break the process and can help the client. It also helps them to formulate a client. How the psychological problems associated with others factor and which factors contribute to made the problems that will easy to understand by this research finding.

Enhanced knowledge on psychological impact and its contributors will be helpful in formulating management strategies as well as facilitating development and upgrade of the current treatment practices and policies. This will add to better services the people with disabilities.

Ultimately, it helps toward better understanding a person with disability and their mental health.

4.3 Limitations of the study

Despite all the efforts to enhance the study, there have been several scopes for improvisation that can be addressed in future studies. The first among these would be the saturation of the core categories which was not extensive enough. More data were needed for a complete saturation of the core categories. However, as this was identified at very late of the analysis, further data collection was not possible considering the time limited nature of this research. Maximum variation of sampling is another area that needed further enhancement. There were some categories which would ensure further variation, for example, individual with immediate onset of disabilities. Inclusion of such participants would ensure a wider understanding of the problems. The study only incorporated the negative aspects of the family and the society. Although this was justified by the objective of the present study, exploration of positive and supportive aspects of the them could be useful in gaining a comprehensive understanding. This can also be addressed by future study.

4.4 Recommendations

In the life individuals with disabilities, mental health is an important aspect. According to the present study there are many factors that contribute towards the development of mental health problems among the people with disabilities. We should find out the associations among them and do preventive work. The Australian Bureau of Statistics revealed in 2008 that a high proportion of the people who have mental disorders do not seek or receive mental health treatment. Moreover when people with disability also suffer from psychological problem then it would be more difficult for them to seek or receive mental health treatment. Therefore mental health and disability awareness need to be integrated into the social policy and the healthcare delivery system at all levels, so that they can easily access

the treatment. There is need to integrate psychological services with other health and social services. So, it is highly recommended that specialized services be provided for the people with disabilities.

The present study is the first of its kind in Bangladesh. The proposed model is at a preliminary state of theorizing. To develop it further into a theory, a long-term outcome research is required. Further comprehensive studies in this area may help in designing and evaluating the existing interventions for the people with disabilities. In this study, the researcher has tried to cover all sorts of disability, but studies are needed for all the sub-groups to provide us with clear pictures about those groups of people. So, further specific area-wise research is needed.

4.6 Conclusion

With the purpose of identifying the developmental process of mental health problems among the people with disabilities, this study was conducted through a grounded theory approach. Interviews conducted with nine participants identified six themes and three categories with corresponding 45 subcategories. With these, the researcher has built a proposed model on the developmental process of mental health problems in the people with disabilities. This model offers a better understanding of mental health problems of the people with disabilities. The proposed model may be considered as a very early step towards building a comprehensive theory which should have explanatory and predictive power. As the generalization of formula theory was not at all within the scope of the present study, so further research is needed to enhance the applicability of this model. Based on the findings of the present study, it can be said that psychologists are urgently needed for identifying, assessing, managing and reducing the rate of psychological problems in the people with disabilities.

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APPENDICES

Appendix A

Demographic Information

Date:

Code:

Gender:

Age:

Types of Disability:

Severity of impairment:

Treatment received:

Excess to Equipment:

From when he/she was disable: By born / Accident

Education:

Occupation:

Training:

Religion:

Family members:

Family income:

Source of income:

Place of living:

Socio-economic status:

Living arrangement:

Appendix B

গবেষণায় অংশগ্রহনকারীর জন্য ব্যাখ্যামূলক বিবৃতি

আমি রিফাত শারমিন ফেরদৌস, ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা মনোবিজ্ঞান বিভাগের এম. ফিল পর্যায়ের একজন প্রশিক্ষনার্থী ও গবেষক। বর্তমানে আমি মনোবিজ্ঞান বিভাগের চেয়ারম্যান ও অধ্যাপক ড. পারভীন হক এবং চিকিৎসা মনোবিজ্ঞান বিভাগের সহযোগী অধ্যাপক ড. মুহাম্মদ কামরুজ্জামান মজুমদার এর তত্ত্বাবধায়নে প্রতিবন্ধি মানুষদের নিয়ে গবেষণারত। এই লক্ষ্যে আমি আপনার সাথে কিছু সময় ধরে কথা বলতে আগ্রহী। এতে আপনার ৬০ থেকে ৯০ মিনিট সময় ব্যয় হতে পারে। কিন্তু আপনার দেয়া তথ্যের গুরুত্ব অনুসারে পরবর্তীতে আরও এক বা একাধিক বার আপনার সাক্ষাৎকার দেয়া প্রয়োজন হতে পারে। প্রয়োজন অনুসারে আমি তার সময় ও তারিখ আপনার সাথে আলোচনা করে ঠিক করে নেব। যে সকল বিষয়ে আমি আপনার সাথে কথা বলব এবং আপনি যে সকল তথ্য প্রদান করবেন তা সম্পূর্ণ গোপন রাখা হবে। কোথাও আপনার নাম, ঠিকানা লিপিবদ্ধ বা উল্লেখ করা হবে না। তবে আমি আমাদের এই কথোপকথন একটি ডিজিটাল রেকর্ডারে রেকর্ড করতে চাই। রেকর্ডকৃত কথোপকথনই আমার গবেষণার মূল উপাত্ত। গবেষণাকর্ম শেষ হয়ে যাবার একটি নির্দিষ্ট সময় পর কথোপকথনের সম্পূর্ণ অংশ মুছে ফেলা হবে এবং গবেষণা ছাড়া কোথাও এই তথ্য ব্যবহার করা হবে না। আমি যে সব বিষয়গুলো নিয়ে কথা বলব তার অনেকগুলোই আপনার পূর্বস্মৃতি ও আবেগ বিষয়ক হতে পারে এবং এসব আলোচনায় আপনার মন খারাপ হয়ে যেতে পারে বা এটি সাময়িকভাবে আপনার মধ্যে অস্বস্তি বা কষ্টের উদ্বেক করতে পারে, কিন্তু এটি আপনার মধ্যে কোন দীর্ঘস্থায়ী ক্ষতির কারণ হবে বলে মনে হয় না। ইচ্ছে করলে আপনি আংশিক বা সম্পূর্ণ প্রকল্পে অংশগ্রহন করা থেকে বিরত থাকতে পারেন এবং গবেষণার যে কোন পর্যায়ে আপনার অংশগ্রহন প্রত্যাহার করতে পারেন।

যদি আপনি এই গবেষণার ফলাফল সম্পর্কে জানতে চান তাহলে অনুগ্রহ করে আমার সাথে (রিফাত শারমিন ফেরদৌস) ইমেইল (dana.globalstudy@gmail.com) অথবা ফোন (০১৭১২১৯৭৩৭৯) এর মাধ্যমে যোগাযোগ করবেন।

আপনার সহযোগীতার জন্য ধন্যবাদ।

.....

রিফাত শারমিন ফেরদৌস

Appendix C

গবেষণায় অংশগ্রহনকারীর সম্মতি পত্র

এই সম্মতি পত্রটি গবেষণার রেকর্ড হিসেবে ঢাকা বিশ্ববিদ্যালয়ের (Dhaka University) গবেষকের কাছে জমা থাকবে।

গবেষণার শিরোনাম: Mental Health Problem among Persons with Disability

আমি রিফাত শারমিন ফেরদৌস এর উপরোলিখিত গবেষণা প্রকল্পে অংশগ্রহন করার জন্য সম্মতি দিচ্ছি। আমাকে গবেষণা প্রকল্পটি সম্পর্কে বিস্তারিত ভাবে বুঝিয়ে বলা হয়েছে এবং আমি এই সংক্রান্ত ব্যাখ্যামূলক বিবৃতি পড়েছি (বা আমাকে পড়ে শোনানো হয়েছে) যা আমার কাছে রেকর্ড হিসেবে রাখা আছে। আমি বুঝতে পারছি যে, সম্মতি প্রদানের মানে হচ্ছে:

আমি গবেষকের কাছে সাক্ষাৎকার প্রদানে সম্মতি দিচ্ছি হ্যাঁ না

আমি সাক্ষাৎকারটি ক্যাসেটে রেকর্ড করার সম্মতি দিচ্ছি হ্যাঁ না

আমি প্রয়োজনে পরবর্তীতে আবারও সাক্ষাৎকার প্রদানে সম্মতি দিচ্ছি হ্যাঁ না

আমি বুঝতে পারছি যে, আমার অংশগ্রহন স্বেচ্ছামূলক; আমি ইচ্ছে করলে আংশিক বা সম্পূর্ণ প্রকল্পে অংশগ্রহন করা থেকে বিরত থাকতে পারি এবং গবেষণার যে কোন পর্যায়ে আমার অংশগ্রহন প্রত্যাহার করতে পারি যার জন্য আমাকে কোন ভাবেই ক্ষতিগ্রস্ত করা হবে না। এছাড়া গবেষণায় একক সাক্ষাৎকার বা দলীয় আলোচনার মাধ্যমে যে তথ্য আহরন করা হয়েছে তার প্রকাশনা বা উপস্থাপনায় কোন অবস্থাতেই অংশগ্রহনকারীর নাম-পরিচয় লিপিবদ্ধ থাকবে না বা প্রকাশ করা হবে না। আমি আরও বুঝতে পারছি যে, আমার থেকে আহরিত তথ্যের একটি লিখিত অনুলিপি আমাকে দেয়া হবে যা দেখে আমি সেটি গবেষণায় অন্তর্ভুক্ত করার বিষয়ে সিদ্ধান্ত দিতে পারি। এবং আমি যা তথ্য দেব তার গোপনীয়তা রক্ষা করা হবে, ও এমন কোন তথ্য কারো কাছে বা কোন রিপোর্টে প্রকাশ করা হবে না যা থেকে আমাকে চেনা সম্ভব।

অংশগ্রহনকারীর নাম:

স্বাক্ষর: বা টিপসই:

তারিখ:

Appendix D

টপিক গাইড

- আপনি যে চোখে দেখতে পান না সে সম্পর্কে কিছু বলুন?
- এই বিষয়টি আপনার জীবনে কিভাবে প্রভাব ফেলেছে?
- এই বিষয়ে আপনার সবচেয়ে কষ্টের অনুভূতি কি?
- পরিবার আপনার সমস্যাটিকে কিভাবে দেখে?
- সমাজ আপনার সমস্যাটিকে কিভাবে দেখে?
- এই বিষয় নিয়ে আপনার মনের মধ্যে কেমন লাগে?
- কবে থেকে আপনার সমস্যাটি শুরু হয়েছে?
- মানসিক সমস্যা বোধ করলে আপনি কি করেন?
- কোন বিষয় গুলো আপনাকে মানসিক কষ্ট থেকে মুক্ত থাকতে সাহায্য করে?
- ভবিষ্যৎ সম্পর্কে আপনার ভাবনা কি?

Appendix E

Key Words

- বাতাস
- অসহায়
- বারান্দা
- সুন্দর
- মুরগী

Appendix F

Translated codes

Bengali	English
হাঁ... হ... ও বসে বসে খাও, আর ইয়া করো	<i>"My wife told me offensively – Okay, sit, eat, and do nothing. That is what you are good at."</i>
না, ভাবেই, ভাবেইতো পরের না। হুম... পর ভাবেই বোঝাই। হুম... মায়ের নাহান। মায়ের লাহান কবি না যে এটা আমার বোঝা নয়। এটা আমার সন্তান, হুম... ওদের কাছে এখন বোঝাই।	<i>"Yes, they (brother and sister in laws) felt that. They are not like my mother who would say, this is my child, not a burden to me. Yes, I am a burden to them."</i>
যেখানে আমাদের পরিবারগুলোই আমাদের support দেয় না। আপনি কোন organization বা institution এর মাধ্যমে কিভাবে support দিবেন।	<i>"When our families do not support us, how is it possible for other organizations or institutions to support us?"</i>
এটা আগে পরিবার জায়গা থেকে আসা লাগবি, পরিবারের লোক ই এখন এই প্রতিবন্ধী যারা আছে তাদের ঠিকমত দেখে না	<i>"Care should come from the family first. Yet, the family members don't take the proper care of these people with disabilities..."</i>
পরিবার সবসময় আমাকে তো অত গুরুত্ব দিচ্ছিল না, তেই অকর্মা এখন কাজ করবার পারতেছিল না, কি করবি, তাই থাক ওটি	<i>"The family always denies me any importance. They say, 'he is useless; so keep him away from this matter.'"</i>
কিন্তু এখন আর ডাকত না তই তখন খুব খারাপ লাগত	<i>"As no one calls me to discuss any family matter, I feel very sad..."</i>
"এই ল্যাংড়াটা এই কাজ করল।" আমি এরকম বলেই আমাকে এরকম অসম্মান করে কথা বলে	<i>"They said, the 'langra' (a very derogatory term for a person with physical disability) did this or the 'langra' did that. They could say that as I am a disabled."</i>

<p>তারা সে সম্মান দিতে চায় না। আপনি আমার কাছে কেন সমাজের লোকের কাছেও জিগাসা করেন তাহলে বলবে প্রতিবন্ধীদের তারা সহযোগিতার চোখে দেখে কিন্তু ভারসাম্যর ভাবে দেখে না।</p>	<p><i>"They do not want to respect. It is not only my opinion, if you ask the people of the society, they too will say that they have sympathy for us, but they don't believe in equal rights."</i></p>
<p>বেশীর ভাগ সময় সমাজ আমাকে মনে করিয়ে দেয় যে তুমি দৃষ্টি প্রতিবন্ধী</p>	<p><i>"Society never forgets to remind me that I am blind."</i></p>
<p>প্রতিবন্ধী মানুষদের সাথে এই বৈষম্যটি করা হয় কারন তারা মনে করে প্রতিবন্ধী মানুষ দুর্বল, অক্ষম বা তারা capable না।</p>	<p><i>"...this discrimination happens with the disable people, because they (the society) think that the disabled are weak and incapable."</i></p>
<p>কিন্তু কখনই আমি কাউকে পাইনি যে আমার কথা শুনেছে। তারা কথা এক কান দিয়ে শুনে আরেক কান দিয়ে বের করে দিচ্ছে</p>	<p><i>"But I never found anyone who would listen to me. They do not even bother about me."</i></p>
<p>যদি কোন ছেলেকে জিজ্ঞাসা করি কোথায় যাচ্ছিস তাহলে বলে কাটার বাড়ি যাচ্ছি, ল্যাংড়ার বাড়ি যাচ্ছি জিনিষি আনতে। আমার দোকানে বসে আমার সামনে বসেই বলছে কিন্তু সে অনুভব করতে পারছেনো আমার সামনে বললে আমার কেমন লাগে। কিন্তু ওকে বললে হবে কি আমাকেও সেটা লাগে।</p>	<p><i>"It has happened many times. I asked someone about where he was going. He replied that he was going to bring something from Kana's house or Langra's house (kana and langra are very derogatory terms for person with physically disability). He said right in front of me, as if it means nothing. He didn't even think about how I would feel about this. He said it to someone else, but still it did hurt me."</i></p>
<p>আমরা ছোটবেলায় স্কুলকে বলেছি ক্লাসরুমকে change করার জন্য কিন্তু তারা কেউ শোনেনি। এখানে অল্প একটু ব্যয় বেড়ে যাবে বলে শিক্ষাপ্রতিষ্ঠান এটা করার বিষয়ে আগ্রহী নয়। একই বিষয় সবজায়গাতে।</p>	<p><i>"When I was a child, I begged them to change the arrangement of the classroom, but the authorities didn't pay any attention. The change of arrangement would raise the expenses a little. That's why they didn't do it. The schools were never interested in this. The problem is the same everywhere."</i></p>

<p>আমাদের সমাজের মানুষের ধ্যান ধারণা গুলো আত্মকেন্দ্রিক। আরেকজন মানুষের জন্য পাঁচ মিনিট সময় ব্যয় করবে তার সময় নেই।</p>	<p><i>"The attitude of the people of our society is always self-centered. They have no time to spend on other people's problems."</i></p>
<p>আমার হাজবেন্ড আমাকে ঠিক আমি যে তার ওয়াইফ, মিসেস কারো কাছে পরিচয় করতে তার বাধত আগে কারো কাছে বলত না যে আমি তার ওয়াইফ, আমি আমার বোন বা আমার কেউ কোন ভাবী টাবি বা অন্য যে থাকে সবার সাথে সবার পরিচয় করাচ্ছে আমাকে তো পরিচয় করানোর মত কেউ নাই সে দেখতাম ইতস্ত থাকত, তখন মনে হত যে আমার চোখটা এই রকম সমস্যা তো আমার সাথে পরিচয় করতে তার মানে খারাপ লাগছে</p>	<p><i>"My husband never feels comfortable to introduce me as his wife; he tries to avoid it when he is in some parties or any social gatherings. He is at ease to introduce his mother, sister or sister-in-law. But, when I urge him to introduce me, I see him hesitate. Then I know my eye problem is the reason for his hesitation."</i></p>
<p>আমি দেখতে পাচ্ছি যে সে আমাকে এড়িয়ে যেতে চাচ্ছে। আর বিষয়টি আমি অনুধান করতে পারছি নিশ্চয় তার মধ্যে কোন negative ধারণার উদয় হয়েছে। তার ফলে আমাকে এড়িয়ে যাচ্ছে।</p>	<p><i>"I was clearly seeing that he had been avoiding me. I realized that he had some negative thoughts about me. That's why he avoided me."</i></p>
<p>সমাজের মানুষ বলে, মানুষ অনেক কয় যে চোখ নাই, বিয়ে সাতির ব্যাপারে কয়, কয় অক কেডা বিয়ে করবি। হু... হু... হু... কি করতে পারবি। কাজ কাম করতে পারবেনা। অক লিয়ে যায় কি করবি, অতো যাত, ওকে যায় ফেলায় থুবি, বসে থেকে ভাত দিবি, এগুলো সমাজের মানুষ বলে।</p>	<p><i>"People never forget to remind me, 'You are blind. Who will marry you? What will you do? You can't manage the household work. Who will take you and give you food without having any work in exchange?'"</i></p>
<p>আমি আমার বাব মা সমাজের অনেককে বলি। আমি যখন চিৎকার চেচামিচি করি ও সমাজের মুরব্বীদের কাছে যাই তখন তারা উল্টো আমাকেই দোষারপ করে</p>	<p><i>"I was tortured, and I told this to my parents and other people. When I went to the community leaders for justice, they blamed me instead."</i></p>
<p>Deaf নারী হিসাবে সমাজ বাড়তি কিছু দোষ এমনিতেই আমাকে দিয়ে রাখে। কারণ আমি শ্রবন প্রতিবন্দী নারী।</p>	<p><i>"The society threw some more blames at me. That's because I was a deaf woman."</i></p>

<p>আশেপাশের প্রতিবেশী, চাচাতো ভাইরা মাঝে মধ্যে বলে প্রতিবন্ধী হয়ে এত কিছু করছে। ওদের অবস্থা এত ভাল না। এজন্য আমাকে দেখতে পারে না। এমনি সমানে কিছু বলে না কিন্তু আড়ালে বলে। শত্রুতা করে।</p>	<p><i>"Some neighbors and cousins sometimes muttered, out of jealousy, 'he got so many things despite being a disabled.' Their financial condition was not well. They said nothing in front of me. But they talked behind my back all the time."</i></p>
<p>ও প্রতিবন্ধী ও ঘরে কোনে পরে থাকবে সে কেন ভাল থাকবে। এই বিষয় গুলো তাদের ভাল লাগেনা। নোংরা থাকুক খারাপ থাকুক পদ্ম ফুলের মত কেন থাকবে।</p>	<p><i>"She is a disabled. Why is she in such a nice place? She deserves a dirty place. She should remain in dirt, but she blooms like a flower"</i></p>
<p>তারা মনে করে, প্রতিবন্ধি দিয়ে বিয়ে করাবে তাহলে সন্তান প্রতিবন্ধি হবে। এটা সমাজের কুসংস্কার।</p>	<p><i>"The society holds this superstition that if someone marries a disabled person, their offspring will be disabled by birth."</i></p>
<p>আমি নির্যাতিত হয়েছিলাম। আমি শ্রবণ প্রতিবন্ধী বলেই এই নির্যাতনের শিকার হই।</p>	<p><i>"I was tortured. Only because I was deaf, I was victimized."</i></p>
<p>ফয়দা তো নিতেই চায়। সাধারণ জনগণও সুযোগ নিবে সমাজের লোকজনও সুযোগ নিবে। সমাজে তো আর সবাই ভাল না।</p>	<p><i>"They always seek advantages. Everyone wants to take advantages. There are not many good people in the society."</i></p>
<p>এখন বুঝি। মনে কষ্ট কি যেমন আমার একটা বোন আছে। আমার কোন কিছু ছোট তাকে আমি বিয়ে দিয়েছি সে বাচ্চার মা হয়েছে। সে স্বামীর ঘর করে খাচ্ছে। ভাল থাক সুখে থাক।</p>	<p><i>"I still feel that psychological pain. I have a sister. Although she was younger, she got married and is now a mother. She is living happily with her husband and I am left alone only to bless her."</i></p>
<p>মনে হতো এই জীবন থুয়ে কি হবে। বেচে থেকে কি লাভ</p>	<p><i>"Sometimes I thought why I should live; there was no reason for that."</i></p>
<p>তখন মনে হয় আল্লাহ কিসেগহিনি আমাকে বানাইছিলো।</p>	<p><i>"Then I thought why did Allah create me?"</i></p>
<p>যে মনে করেন কল্পনাও করতে পারে না একা একা কোথাও যাবে। ওর মনে হয় বাধ্যতা। মনে হয় জালের মধ্যে বন্ধ করা। ঐ বন্দী অবস্থায়। যেমন আমারই মনে হয়।</p>	<p><i>"...a person with physical disability cannot even imagine going anywhere alone. He feels bound. It feels like being trapped in a net. Like imprisonment! For example, I too feel the same."</i></p>

<p>সত্য কথা বলতে কি সাধারণ মানুষের যে সমাজ সে সোসাইটি আমার না। তাদের সাথে আসলে আমাদের দেখা দেখির কোন বিষয়ই নেই। কারণ তাদের সাথে আমাদের যোগাযোগই হয়ে ওঠে না। আমরা এলিয়ান এর মত main strim society তে যাই। তার আমাদের বুঝতেই পারে না।</p>	<p><i>“The truth is the society is for the normal people, not for us. There is no such thing as how we view each other, because, there is no communication between us. We are alien to the mainstream society. They do not understand us.”</i></p>
<p>আমি খুব কষ্ট পেতাম ছোট বেলায়। আমার কাছে মনে হতো যে পৃথিবীতে আমি একাই শ্রবণ প্রতিবন্ধী আর সবাই কথা বলতে পারে</p>	<p><i>“I felt a lot of pain in my childhood, as I thought I alone was deaf and everyone else could talk except me.”</i></p>
<p>প্রতিবন্ধী বিয়ে করলে বাচ্চা প্রতিবন্ধী হয়। আর আমি নিজেই প্রতিবন্ধী, আমার ভারসাম্য রক্ষা করতে পারি কম তাহলে কি করে কি করব।</p>	<p><i>“If I marry a disabled person, our offspring will be disabled hereditarily. I am a disabled person. I could not balance myself. Then how would our offspring manage things?”</i></p>
<p>মার্কেট করতে গেলেন, কিনে আনলেন, পইরলেন। ইচ্ছা করলেন ১ টা জিনিস খাবার মন গেলো, ১ টা কাজ করে, চাকরী করলেন, চাকরী কইরা টাকা ইনকাম করলেন, টাকা লিয়ে এসে সেই জিনিসটা কিনে লিয়ে এসে আপনি খাইলেন। আমারতো এইগুলো কোনও কিছুই করতে পারি না।</p>	<p><i>“If you wish to eat something, you could do any job and earn some money and then you could buy the food and eat it. If you fancy a cloth, you could go to the market and buy and wear it. But, we could do none of these.”</i></p>
<p>কত বছর হয়ে যাচ্ছে আমি বাহিরে কখনও যাইনি। কারণ বাহিরে পেশাব পায়খানার সমস্যা। কে নিয়ে যাবে কন। যদি এক জায়গায় যাই আর পেশাব আসে তাহলে সমস্যা না। এজন্য আমি কোন জায়গায় যাই না।</p>	<p><i>“I have not gone outside for many years now due to the lack of toilet facility. Who would take me out? If I go somewhere and need a toilet, won't it be a problem? That's why I don't go anywhere.”</i></p>

<p>আগে বাংলাদেশে শ্রবণ প্রতিবন্দী মানুষদের শিক্ষার কোন ব্যবস্থাই ছিলো না। আপনি জানেন বাংলাদেশে মাত্র ৭ টি স্কুল আছে তাও Class-8 পর্যন্ত পড়ার ব্যবস্থা আছে। আগে five পর্যন্ত পড়া যেত। এটা শুরু হয়েছে ৫-৬ বছর আগে।</p>	<p><i>"Previously, there was no educational arrangement for the deaf people in Bangladesh. Do you know that now there are only seven schools in Bangladesh for the deaf? These schools have the facilities to educate students up to Class Eight only. In the past, it was only up to Class Five. This program started probably 5-6 years ago."</i></p>
<p>আমাদের দেশে এনজিও দের মধ্যে বেশ দ্বন্দ্ব থাকে একটা এনজিও আরেকটা এনজিও কে পছন্দ করে না। তাদের কাজকে বাধা দেয়, এটা হওয়া ঠিক না।</p>	<p><i>"In our country, there are some conflicts between the NGOs. One NGO doesn't like another. Their inter-conflicts make the job more difficult. This is quite upsetting."</i></p>
<p>আমি communicate করতে পারছি না এটাই আমার বড় কষ্ট। আমি আমার কথা share করতে পারছি না। আমার sharing এর অনেক বিষয় আছে। আমার অনেক সমস্যা আছে যা আমি আমার স্বামীকেও বলতে পারি না। আমার কিছু মেয়েলী সমস্যা আছে তা আমি কাকে বলব। আমার বলার কেউ নেই।</p>	<p><i>"I can't communicate, which is very painful. I can't share my opinions. I have many issues to share. I have so many problems that I can't even share with my husband. When I have some gynecological problems, I feel very helpless and find no one to describe the exact problem."</i></p>
<p>আমরা চমৎকার কিছু কাজ করেছি, সেগুলো মন্ত্রনালয়গুলোতে আলোচনাও হয়, তারা জানে আমরা অধিকারভিত্তিক কাজ করি, কিন্তু ফলটা কি আমাদের documents গুলো নিয়ে তারা ফাইলে তালাবদ্ধ কবে রাখে। কাজের কাজ কিছুই হয় না এগুলো আসলে বড় বাধা।</p>	<p><i>"We did some great work. Those were also discussed in the ministry. They knew that we worked for establishing the disabled people's rights. But the outcome is zero. They filed our document and put it on ice. As a result, we had to suspend our program. This is one of our major obstacles."</i></p>
<p>কেউ নাই যামু কোথায় ? কোথায় যাবো ? এতো কষ্ট ! কষ্ট করে জীবনডাই যাচ্ছে। ছোটবেলা থেকে বড় হয়ে গেলাম, এই পর্যন্ত আমার জীবনে কষ্টতে কষ্টেই যাচ্ছে।</p>	<p><i>"I have no one. Where should I go? So much pain! My life has been a continuum of such pain. I have grown up bearing this pain."</i></p>

<p>যে কয়দিন বাঁচবেন এই কয়দিন এইগ্লার প্রয়োজন প্রয়োজন এগুলো। এগুলো কেডা দিবি। বহন করবি কেডা। কি কইরা খামু। ১ টা জমি নাই, যে করে খামু। কিছু নাই গরীব মানুষ। এগুলো খুব অনুভাব করি।</p>	<p><i>"I will need these things as long as I live. Who will provide these? Who will bear the cost? How will I earn? I have no land to work on. I don't have anything. I am poor."</i></p>
<p>তখন আমার নিজে এ জায়গায় অক্ষম মনে হয়। আমার এ জায়গায় ঘাটতি আছে। ঘাটতিটা তখন আমাকে মনে করিয়ে দেয়।</p>	<p><i>"Then I feel incapable. I have some limitation. My limitation reminds me of my incapability."</i></p>
<p>মনে করেন একটা অনুষ্ঠান হচ্ছেসেখানে আমাকে যেতেই হবে। যেতে ইচ্ছা হচ্ছে এবং যেতে বাধ্য। কিন্তু তখন যেতে পারি না কারণ আমার সমস্যা তো সমস্যাই আমি ওখানে গেলে অন্য জনেরও সমস্যা হয় তখন আর যেতে পারি না।</p>	<p><i>"Suppose I have to attend a program. I want to go and it is really necessary for me to go. But my presence could make trouble for others. So I can't go."</i></p>
<p>হ্যা, মনে করলেন যেখানে যাব সেখানে আমাকে ধরার জন্য দু'জন লোক লাগবে। মানে যেখানে আমাকে কাজ করার জন্য যাওয়া উচিত ছিলো সেখানে উল্টো আমাকেই আবার টানা লাগছে।</p>	<p><i>"Yes, if I go somewhere I need two persons to carry me. That means whenever I want to do a job, I have to engage more people."</i></p>
<p>দাম নাই একটা পুরানো কাপড়ের যে দাম লাই ওইরকম যারা প্রতিবন্ধী তারা ওইরকম পুরনো কাপড়ের মতন</p>	<p><i>"We don't have any value. Disable people are just like old cloths."</i></p>
<p>কিন্তু তারা বলেছে আমার সময় নাই, আমার পারাপারি, তুই পরে আয়</p>	<p><i>"...they used to say that they (family members or other people) did not have time, they were in a hurry. I should come later."</i></p>
<p>আপনাকে আর কি বলব, এখানে (যে ঘরে বসেছিলাম) ছিলো গরুর ঘর। ঐপাশে গরুর ঘর ছিলো আর এই পাশে ছিলো আমার ঘর। ওখানেই আমাকে থাকতে হতো।</p>	<p><i>"There is nothing more to say. There was a cowshed beside my room. I had to live there."</i></p>
<p>খুব কষ্ট পেয়েছিলাম যে আমার হাজবেড আমাকে মহিলা বলে সম্বোধন করছে, নিশ্চই আমার চোখের ব্যাপারটি সবাইকে এভাবেই বলে এই আরকি।</p>	<p><i>"It was very painful for me when I heard my husband referring to me as 'that lady'. It was only because I was blind."</i></p>
<p>এটা আমার কাছে খুবই দুঃখজনক, কষ্ট যে আমি এক চোখে দেখি আর এক চোখে দেখি না</p>	<p><i>"It was really sad for me, that I could see through only one eye."</i></p>

<p>কিন্তু এখন আর চোখে পানি আসে না। কষ্ট করতে করতে এখন আর চোখে পানি আসে না। কষ্ট করতে করতে এখন আর চোখে পানি নাই।</p>	<p><i>"But now there are no tears in my eyes. After bearing so much pain, my eyes have dried out. I feel nothing now."</i></p>
<p>হ্যাঁ সে ওয়াইফ হিসেবে মেনে নিয়েছে কিন্তু পরিচয় করিয়ে দিতে তার খারাপ লাগছে এই জন্য আমি তার সঙ্গে বাহিরে আমি আগে তো কমই যেতাম</p>	<p><i>"Yes, he had accepted me as his wife, but he felt embarrassed to introduce me to others as his wife. So I rarely went outside with him."</i></p>
<p>আবার কোথাও যেয়ে বন্ধুদের সাথে বসে আছি তখন যদি পেশাব পায়খানা হয়ে যেত তাহলে ওখানেই বসে থাকছি। সবাই চলে গেলে একজনকে ডেকে বলছি এই অবস্থা সে হয়তো এনে বাসায় দিয়ে গেছে। নিজের কাছেই খারাপ লাগছে।</p>	<p><i>"While sitting with some friend in a place, I had to remain sitting although I felt the urge to go to toilet. When everyone had left, I requested someone to take me home. It was very embarrassing."</i></p>
<p>রাস্তা ঘাটে। কেউ আমাকে ছুয়ে ফেলবে এটা ভয় হয়। এখনকার যে লোক গুলো তারা যদি ধরে ফেলে তাহলে কি আমি চলে আসতে পারব। এই বিষয় গুলো অনেক খারাপ লাগে। আর আমাদের ধরতে বেশী চেষ্টা করে।</p>	<p><i>"I am afraid that someone could touch me intentionally on road. If they touch me, I have nothing to do. I am afraid of being abused. I feel panic."</i></p>
<p>কিন্তু আবার যদি ঐ লোকটার সাথে দেখা হয় তাহলে আবার মনে হয় তখন মন খারাপ হয়। মনে হয় একই সাথে থাকি, একই সাথে চলি তুই এই কথাটা আমাকে বলতে পারলি। তুই আমাকে নিজে বললি না কেন। মানুষের কাছেই এই কথা বললি কেন।</p>	<p><i>"...If I met that person again, I would feel bad. I thought we were on a good term. How could he tell those things about me? If he had problems, why didn't he tell me directly?"</i></p>
<p>একজন শ্রবন প্রতিবন্ধী মানুষ হিসাবে আমাদের প্রধান যে কষ্টটা আমরা কোথাও আসলে কোন supportপাই না। সে অন্য কারও কাছ থেকে supportআশা করে কিন্তু কোথাও পায় না। এটা বড় কষ্ট।</p>	<p><i>"As a person with speech and hearing disability, my main pain is that I never get the proper support from anywhere. It is painful."</i></p>
<p>আমার ভবিষ্যৎটা খারাপ হবে। এখন ভাল থাকলে কি হবে আমার ভবিষ্যৎটা খারাপ হবে।</p>	<p><i>"My future would be worse. Although now I am fine but my future would be worse."</i></p>
<p>হ্যাঁ এই জীবন কষ্টের জীবন। যতই সহজ করতে চান কষ্ট থেকেই যাবে। পর্যায় ক্রমে হবে।</p>	<p><i>"Yes, life is painful. Whatever you tried to make it easy, but pain remains. It comes periodically."</i></p>

<p>আসলে একটা মানুষ হাটতে না পারলে তার কষ্ট হয়। শরীরের যে কোন অংশ নষ্ট হয়ে গেলেই কষ্ট হয়। যেমন আপনি একটা স্বাভাবিক মানুষ আপনার একটা হাতমচকে গেলেই আপনার কষ্ট হবে।</p>	<p><i>"Naturally a person feels pain if he can't walk. If any part of the body gets impaired, it becomes very painful for him. For example, suddenly your leg get impaired, you would feel devastated."</i></p>
<p>তবে জীবনের শেষ সময় একদিন কথা বলব ওর মেয়ে যখন বড় হবে, তখন বলব দেখ তুমি আমাকে অবহেলা করছ, আল্লাহ তোমাকে দিয়েছে। যখন তার বিয়ে হবে না, বাবার চোখের সামনে একটা মেয়ে থাকা কতখানি কষ্টের ও তখন বুঝবে।</p>	<p><i>"When his daughter grows up I would tell him that he had neglected me. So Allah gave him a disabled daughter. When his daughter would remain unmarried then he would understand how painful it is for a father to have an unmarried daughter."</i></p>
<p>এই যে এত মানুষ সবাই বেড়াচ্ছে আর আমি পরে আছি। সবই তো ঠিক আছে বুঝতে পারছি, কথা বলতে পারছি কিন্তু সবাই বেড়াচ্ছে আর আমি বেড়াতে পারছি না।</p>	<p><i>"There are lots of people. All of them can move, but I am stuck in one place. Everything else is fine, I can understand, I can talk, but I can't travel."</i></p>
<p>এমনও এক সময় হয়েছিলো যে বেঁচে থেকে লাভ কি। সবাই কথা বলতে পারে আমি কথা বলতে পারি না।</p>	<p><i>"Sometimes I even thought that what point of living was. Everyone can talk. I just only can't talk."</i></p>
<p>রাতের বেলা নিজেই নিজের পায়ে আঘাত করেছি। নিজের শরীরে নিজেই মারতাম। ইচ্ছা মত। মনে হতো এই জীবন থুয়ে কি হবে। বেচে থেকে কি লাভ। মানুষের আশায় আশায় বসে থাকা। বিছানায় পায়খানা পেশাব হয়ে যায়। মানুষ তো এখন সহ্য করছে আর কতদিন করবে। তাহলে প্রতিদিনই কি এরকম গাল খেতে হবে তাহলে এ জীবন রেখে কি হবে।</p>	<p><i>"At night I hit at my leg myself. I beat myself as hard as I could. I thought to myself - why should I live? What would be the purpose of my life? I have to always wait for someone's help. I have to do toilet in bed. How long people will tolerate me? Would I be scolded by them every day? So what is the purpose of my life...?"</i></p>
<p>অসহায়, দৃষ্টি... চোখে দেখি না। কাম কাজ কইরবার পারি না এটা অসহায় লয়। এটা বড় অসহায়</p>	<p><i>"Helpless...cannot see. As I cannot do my work so I feel helpless. It's a great helpless feeling."</i></p>

<p>তখন মনে হয় যে আমার যদি এই চোখটা থাকত তাহলে হয়ত আরও একটু ভাল বিয়ে হত বা আরও একটু ভাল সমাজে চলতে পারতাম, হয়ত আমি সবার কাছে এত ছোট হয়ে থাকতাম না, এই আর কি, নিজেকে ছোট মনে হয়।</p>	<p><i>"Then I thought, if I could see, I might have had a better opportunity for marriage or maintaining a better social life. I would not be so dependent on others. I felt inferior."</i></p>
<p>আমার এমন ধরনের অনুভূতি হয়েছিলো যে আমি নির্যাতিত হয়েও যদি বিচার চাইতে যাই তাহলে বিচার পাবনা। তো আমার জন্য আসলে কোথাও কোন জায়গা নাই।</p>	<p><i>"I have a feeling that if I'm abused or something, then I would not get justice. The community thinks of me as a burden. They would never prioritize my problems over any influential person."</i></p>
<p>Right তখন কারও সাথে কোন কিছু বলতেই ভাল লাগেনা। মেজাজ খিটখিটে হয়ে থাকে। তখন কেউ যদি কথা বলতে আসে তাহলে আমি রেগে যাই। কথা বলিনা।</p>	<p><i>"Yes, then I did not want to share anything with anyone. Then my mood was irritable and if anyone came to talk to me, I became angry. I did not speak."</i></p>
<p>এজন্য আমি কোন জায়গায় যাই না।</p>	<p><i>"For that reason I did not go anywhere."</i></p>
<p>চুপ করে বসে থাকি, ঘুমিয়ে পারি, খাওয়া দাওয়া করতে ইচ্ছা করেনা। কোথাও যাইনা, কারও সাথে মিশিনা কথা বলিনা। দিনের পর দিন ঘুমিয়ে আছি, বসে আছি।</p>	<p><i>"I stay quiet, fall asleep, and did not take food. Did not go anywhere and did not communicate with others. Day after day I passed by sleeping."</i></p>
<p>কোথও গেলে একা তো চলতেই পারতাম না তখন ধরে ধরে চলা ফেরা করতে হতো। যেমন ধরেন স্কুলে আমি বই নিয়ে যেতে পারতাম না। সহপাঠীদের নিয়ে যেতে হতো। বসে দিতে হতো।</p>	<p><i>"When I went to somewhere I could not walk alone. I had to walk with the support of something. For example, I could not carry books to school. My classmates carry those for me."</i></p>
<p>এটা মনে করেন বিরাট কঠিন কাহিনী। বাপ যা দিতো তাই খাওয়া লাগত।</p>	<p><i>"That was a great sad story. I had to eat what my father provided for me."</i></p>

<p>একটা দশ মিনিটের কাজ কিন্তু লোক ছাড়া আমি করতে পারছি না। আমাকে তার জন্য টাকাও দিতে হয়। টাকাও দিতে হবে আবার অনেক সময় লোকও পাওয়া যায় না। আমি সবই বুঝতেছি ওখানে গেলে আমি পাঁচ মিনিটে কাজটা করতে পারব, অথচ করতে পারছি না।</p>	<p><i>“When a simple task needs only ten minutes to do for others, I need an hour. I have to pay for finishing simple tasks that I could do easily if I were a normal person. It is sad when you know how simply a work can be done, but only you are not fit for that task.”</i></p>
<p>আমি নিজেও একসময় ভাবতে শুরু করলাম আমি কিছু করতে পারব না, আমি জড় পদার্থ। যেমন - গরুর জীবন।</p>	<p><i>“I also started to think that I could not do anything. I am inanimate. My life is no better than a cow.”</i></p>
<p>সেটা যদি বলতে হয় তাহলে বলি যে, আমি যখন পড়াশোনা করি অন্য স্বাভাবিক ছেলেদের জন্য যা আমাকেও ঠিক একই সময় দেওয়া হচ্ছে। কিন্তু হয়তো কিছু সময় যদি আমার জন্য আলাদাভাবে ব্যয় করা হতো তাহলে হয়তো আমি আরেকটু ভাল করতে পারতাম। যেহেতু হয়তো আমি ওদের মত করে একই সময়ে cover করতে পারি না।</p>	<p><i>“When I was at the examination hall, I had been provided with the same time as other students. I couldn’t finish the answers. If they gave me some extra time, I would have finished the answers.”</i></p>
<p>এটা আমার কাছে মনে হয়, যেমন চাকরী একটা আমার খুবই দরকার চাকরী করতে যাব কিন্তু দেখা যাচ্ছে যে একটা প্রতিষ্ঠানে আমার এই চোখের সমস্যার জন্য হয়ত বা সেখানে আমাকে নিচ্ছে না, বলছে যে আপনার একটা চোখের সমস্যা আপনি কম্পিউটারে কাজ করবেন বা যেটাই করেন আপনার চোখে দেখতে সমস্যা হবে তার চেয়ে থাক</p>	<p><i>“I need a job badly, but when I went for interviews, they did not select me only because of my vision problem. They made excuses like ‘You have to work on computer. You are not fit for this job’”</i></p>
<p>সবই এক একই পরিবারে আমার দুটো মেয়ে কিন্তু একটু আলাদা।</p>	<p><i>“Everything is the same, we are two girls from the same family, but we are different and treated differently.”</i></p>