

# **The Feminine Dimension of Disability**

*A Study on the Situation of  
Adolescent Girls and Women with Disabilities  
in Bangladesh*

## **Part- I**

**CSID**

**Centre for Services and Information on Disability**

House # 545, Road # 11, Baitul Aman Housing Society,  
Adabor, Shyamoli, Dhaka

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# **The Feminine Dimension of Disability**

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## Foreword

Disability has been globally recognized as a development issue, creating a positive impact on development initiatives even in Bangladesh. Development organizations working on disability related issues are, in fact, at this stage looking for systematic interventions to address the felt needs of the people with disabilities in Bangladesh.

The Centre for Services and Information on Disability (CSID) had the privilege to carry out a study on the situation of the adolescent girls and women with disabilities in Bangladesh. The prime objective of the study was to provide feedback to development planners on the prevailing 'State of affairs' of these girls and women, which might be of some use as input for the development of programs based on the felt needs of the subject group to address the vulnerability and also to assess strengths of their concerned section of people.

The study has provided a wide range of information both quantitative and qualitative covering diversified and complex areas concerning the situation of girls and women with disabilities. CSID could come up with a comprehensive and analytical report on the situation. The job by any count was a challenging one. We could however, face that effectively as the 'Study Team' had the real dedication to do the job properly and with colour. In more plain words, the sincere efforts and dedication of the research team, comprised of persons with an extraordinary depth of understanding on disability and the development context; were the key strength of CSID in undertaking this challenge.

The involvement of Community Approach to Handicap in Development, as a partner, and of the Center for Disability in Development (CDD), which offers training to organizations working with disability issues, had a significant role in carrying out the study. CSID feels honoured to recognize their sincere contribution to the study.

CSID sincerely recognizes the role of the Program for Research on Poverty Alleviation, Grameen Trust, for the support, both financial and technical, they extended in undertaking the study. Also CSID deeply recognizes the support provided for printing by Save the Children Sweden and OXFAM GB.

We are very hopeful that the findings, including recommendations advanced, of the study will serve as an effective tool to update and redesign ameliorative package by the development planners to include the women and adolescent girls with disabilities as a vulnerable class in Bangladesh in a much better way.

**Khandaker Jahurul Alam**

Executive Director,  
Centre for Services and Information on Disability (CSID),  
Dhaka.

## Message

As disability issues are increasingly being recognized as a crosscutting development component, it has been keenly observed that the need for information on the prevailing disability situation in Bangladesh is increasing. It is no doubt a positive indicator that disability issues are getting added consideration in the wider development context. Over the last few years, there have been many attempts at such information collection and dissemination. Quite a good number of studies and researches have also been done. However, the most vulnerable areas of gender discrimination have been overlooked either by design or default.

The “Feminine Dimension of Disability” has successfully reflected on the situation of the adolescent girls and women with disabilities in this context. This was a timely response to the need for a systematic planning of development interventions to address the most critical areas of disability agenda of the country.

CSID is sincerely grateful to the Program for Research on Poverty Alleviation, Grameen Trust, for the, both financial and technical support in this endeavour and also to the Save the Children Sweden and OXFAM GB for providing printing support.

As the chairperson of CSID, I feel proud of such an endeavour, which will perhaps, open the hidden reality in the overall context of disability in Bangladesh. I hope this will stimulate the development planners to think or rethink the issue more carefully, and will ultimately bring a positive change to the fate of the people with disabilities in general and also imbibe them to give a particular focus on girls and women with disabilities.

**Monsur Ahmed Choudhuri**

Chairperson,  
Centre for Services and Information on Disability (CSID),  
Dhaka.

## Acknowledgements

Issues related to people with disabilities in Bangladesh are still dominated by ignorance, fear and superstition in the community. The direct result of this has been the neglect of the persons with disabilities in all spheres of life. Females with disabilities in Bangladesh may be considered to have a double disadvantage, as they are already socially discriminated against their male inmates within this patriarchal society.

There have been a number of studies by development organizations on the general situation of the people with disabilities in Bangladesh, but the issues of women with disability have not been adequately examined. It was therefore, my great pleasure to accept the challenging task of undertaking an intensive study on the situation of the females with disabilities in Bangladesh that the Centre for Services and Information on Disability (CSID) offered me.

Although the findings are limited and have their shortcomings, the research team is confident that the outcomes reflect the ***Feminine Dimension of Disability*** in Bangladesh. We believe that the findings will provide input to development planners for developing systematic interventions in addressing the unique and formidable challenges facing these girls and women.

On behalf of the study team, I acknowledge the contribution of the development partners and their well-trained staff members, the Community Handicap and Disability Resource Person (CHDRP) in particular, who have collected data and information on the respondents. It was a significant strength of the study that the CHDRPs have been very much involved with the respondents, which allowed them easy access to sensitive areas of information. Lastly, I owe thanks to the respondents for their sincere responses to the questionnaire; they are the key contributors to this study.

**Nirafat Anam, Ph.D**  
Principal Researcher.

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# Executive Summary

Disability issues in general demand a wide range of program coverage relating to all common types of disability prevailing in the community. Development of effective and efficient program interventions and strategy requires free availability of adequate support materials and documents on different issues related to disability. In recent times development organizations have taken extensive programs for the empowerment and development of women in Bangladesh. But limited emphases as well as efforts have been laid on the women and adolescent girls with disabilities.

Centre for Services and Information on Disability (CSID) is a development organization working with disability with intensive focus on study and research on disability related issues. It has undertaken an intensive study on situation of the disabled women and adolescent girls with disabilities. Initially the study has been carried out in association with the 'Program for Research on Poverty Alleviation' of Grameen Trust. Later two other developments partners viz. (a) OXFAM-GB, and (b) Save the Children Sweden supported the printing and publishing job of the study respectively.

## **Study objectives:**

The prime objective of the study is to come up with a comprehensive socio-economic and psychological analysis of the status of women and adolescent girls with disabilities in Bangladesh aiming to provide information to the development program planners for designing and implementing need-based development interventions for the women and adolescent girls with disabilities.

## **Methodology:**

The study has been carried on applying a variety of techniques and tools to find-out appropriate and authentic information from different geographical areas of Bangladesh on issues related to women and adolescent girls with disabilities. A research team comprised of researchers and disability program managers analyzed the data obtained from 21 districts involving field level trained disability resource people<sup>1</sup>.

Information's have been collected from 310 respondents through a set of pre-tested questionnaire. Fifty case studies of girls and women with disabilities have been studied for detailed and qualitative information. Focus group discussions were also conducted with community groups in different geographical areas. Person-to-person conversations have been made with individual respondents for obtaining in-depth and real information.

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<sup>1</sup> Trained disability workers working with different development organizations.

## **The Summary of the Study Findings:**

*(Reflections and analysis from case studies, data findings, focus group discussions, and one-to-one conversations)*

The study team after compilation and analysis of the data collected through questionnaire, focus group discussions and conversation with relevant individuals and review of case studies came up with the following findings. The findings do reflect the factual situation of the girls and women with disabilities with indications to the different areas of concern.

### **Types and degrees of disability:**

The breakup or distribution of disability among the adolescent girls and women with disabilities broadly appeared the same to the national average. The major group has physical disability, 37.33% among adolescence girls, and 40% among women. Speech and hearing, visual and intellectual disabilities come to the next categories. Multiple disability were seen the least at a compiled figure of 10%. As to the degree of disability, the 'moderates' rest on the top at 36.13%. The lowest is the 'profound' category at 9.35%. The interesting point to note is that in 'severe' category, the percentage of affected girls with disability is higher in comparison to woman with disability. It is really eye-catching.

### **Treatment:**

Data revealed that 93.33% of girls and 97.50% of women with disabilities had at some stages of their lives received some kind of treatment for their impairment and disability. At times, as the data indicate that when it appears that no cure is possible, most families become hopeless and refrain from seeking further services (though essential) for girls and women with disabilities. This disillusionment or apathy pays a heavy toll on the girls and women with disabilities. The respondent families of the girls and women with disabilities had sought treatment from a varied range of sources even at high costs. The family members paid about 89% of the treatment costs. This indicates the state of poor health service delivery to the persons with disabilities at state level, which has mandatory obligation to deliver such minimum medi-care cost free. That is the poorest of the poor even do not get the bare basics of health services.

### **Education:**

Disability is a barrier to education. Only 3.75% proceeded to university education in the woman with disability group. The highest enrollment can be seen at the primary school level at 21.25% for women with disabilities and 30.67% for girls with disabilities respectively. Most of the girls and women with disabilities who are pursuing education have to attend in formal schools due to the existing provision of free primary education. The second highest numbers of learners attend in non-formal educational institution. Enrolment in special education is much lower.

A massive 64% (average figures of girls and women with disabilities combined) dropout rate occurs from primary to secondary level. 36.06% of the women with disabilities and 36.58% of the girls with disabilities were either teased or their venture to study were not supported (not in favour) by other members of their surrounding environment.

Accessibility to the educational institution is one of the major problems for girls and women with physical disabilities. Girls with disabilities residing in hostels face problems due to absence of female house parent which limits sharing of feminine and other essential needs. The most humiliating thing is that the teachers are also involved in teasing their disabled learners.

In spite of all of these inconveniences and handicapping environment, the girls and women with disabilities have potentials to be in mainstream education. Some are in education process where their disability is not visibly identified.

### **Employment:**

It was discouraging to note that very insignificant number of respondents (3.21%) from the two groups were involved in full time income generating activities. 64.52% were sitting idle with no work. However some of them, particularly the women with disabilities (21.88%) were somehow earning some income through different activities mostly in the informal sector.

Although the number is not mentionable, some women with disabilities are engaged in multi-sectoral jobs like office job, teaching, small business, day-labourer, housemaid, handicrafts worker, dairy & poultry raising, sewing, and house-hold works etc. In most cases they managed to arrange the job themselves with out any external support.

The income of the women or girls with disabilities is mostly spent in meeting the family needs but their family and the society do not always encourage the engagement in jobs/works of the girls or women with disabilities.

### **Marriage, conjugal relationship and dowry:**

The involvement in romantic relationship ranks very high in life's priorities for most women. The study focused on such personal factors like attitudes toward marriage, behavioural aspect, the effect of disability on the partner's behaviour; environmental factors, social attitudes and family expectations of the respondents.

Situation is reversed in case of women or adolescent girls with disabilities. Arranged marriage is still customary in the society of Bangladesh. The percentage of adolescent marriage is 48% (Afrin, 2000). This is discouraging, yet the family can find spouse. The rate of marriage of adolescent girls with disabilities is only 2%. One of the major causes of the frustration of women with disabilities and their families is people are hesitant to marry a disabled girl. Most of the marriages of women with

disabilities took place against consideration or offering of big amount of cash or kind, even land as dowry.

### **Community and family attitudes:**

The overall development of a girl or woman with disability depends on the attitudes of the people or community surrounding them. In cases of positive attitudes from family, and other concerned in the society, the girls or women with disability seems to be more confident and have success in life while the negative attitudes made the girl or woman with disability depressed, dependant and a person with low self-esteem.

It revealed that only 7.10% participated in games and sports. A larger, yet still negligible, number of the respondents, 26.13%, participated in social activities. However, figures state that actual participation is low by women and girls with disabilities, but in terms of their intention to participate, the response is satisfactorily high. 53.5% reported that they were interested to participate, while only 7.5% commented that they would never like to participate.

In the adolescence group, the families with members in between 6 to 10 numbered highest with figures of 80 (53.33%). Families with members in between 1 to 5, numbering 65 (43.33%) come next. For a larger family it is possible to share the care-time required for the disabled family member.

### **Abuse:**

Women with disabilities appear to be at high risk for emotional, physical, and sexual abuse. The prevalence of abuse of the girls and women with disabilities was 92% for both groups. At most the equal percentage of women and girls with disabilities reported emotional abuse (78% and 75%), incidents of physical abuse (82% for both) are also same. And cases of sexual abuses (32% and 37%) have however, little difference.

In many cases parents also abuse the girls and women with disabilities. Most of the incidences of sexual abuses occur among the girls and women with intellectual disabilities. In the second frequency of sexual abuse towards girls and women with disabilities goes to hearing impairment. This is surprising to note that the traditional healers abuse the girls and women with disabilities sexually in the name of offering therapy or treatment. Not only the abused girls and women even their family members do not feel comfortable to disclose such cases of abuses because of social threat or embarrassment.

### **Reproductive health:**

Most of the girls and women are not much aware of the issues related to the phases of reproductive health. People identified disability, particularly of the women, as a risk factor for reproductive health.

The society is still conservative to discuss reproductive health issues. The parents (even mothers) do not share any sexual and reproductive health issues or information with their daughters. Most of the adolescent girls get idea about the phases of physical development and transition period (internal transformation or menstrual) from peers, elder sisters, sister-in-laws, grandmothers etc. Majority of the girls with disabilities had experienced serious problem of shock, phobia, depression, and embarrassment while facing period. Especially the girls with speech and hearing impairment face difficulty in passing this period due to limited communication capability.

### **Physical growth:**

Natural physical growth is a normal development process in the human body due to hormonal changes. The physical change also effects changes in behaviour and attitudes of a person, but in case of intellectual disabled, family could not measure or notice such physical changes that are usually expected and hence they became worried.

### **Psychological phenomenon:**

The psychology of the girls and women with disabilities is dependent on many emotional, environmental and social factors such as self-assessment, personal acceptance, family and social attitude, isolation and etc.

Many girls and women even with minor disabilities are facing problems of acceptance in their families. Segregation from the society and family was common feature for girls and women with disabilities in many cases. In many cases, the girls and women with disabilities were segregated even at their work places.

It is evident that the girls and women with disabilities are deprived of their 'Basic Human Rights' like food, clothes, education and treatment etc. That creates negative influence on overall psychological development or mindset of the disabled women and girls. Sexual abuses in many cases have caused stressful situation on the psyche of the girls and women with disabilities, which ultimately made them isolated and frustrated.

### **Human rights issues:**

The very right to security of human life has been violated on many occasions when it relates to the girls and women with disabilities. They had been sexually abused, physically tortured, verbally abused. Even in some cases they became disabled due to violence etc. inflicted upon them. They did not even get opportunity to demand justice. Moreover, they were blamed as guilty because of handicapping environment.

The girls and women with disabilities are usually deprived of getting access to treatment and health care facilities. Social beliefs and superstitions in many cases caused such deprivation. They have been deprived of the rights of basic education. The school authorities in many cases refused to enroll the girls with disabilities



although they had potentialities. This is a violation of the right to education defined in the Declaration of Education for All and the National Disability Policy.

Communication is a basic human right but there is no such recognized communication mechanism (Bangla Sign language) for the speech and hearing impaired persons in the country.

### **Ability, dignity and self-esteem:**

Majorities of the girls and women with disabilities including severe level of disabilities have the confidence to be educated and subsequent engagement in contributing activities. Many of them have skills in trades like sewing, cooking, painting, handicrafts, tailoring, dairy and poultry raising and etc. There are evidences of extraordinary achievement by severely disabled women. Some of the girls and women with disabilities who had luckily access to employment, developed romantic relationship with the desired one and are now living a happy married life. The self-esteem of the girls and women with disabilities is more strongly influenced by social and environmental factors.

# Introduction

## **Introduction to CSID:**

The Centre for Services and Information on Disability (CSID), a registered trust, is a non-government organization involved and engaged in providing support services to development organizations and communities with a view to facilitating activities directed towards the persons with disabilities in Bangladesh.

## **The broad objectives of the CSID:**

- a. Provide necessary information on various disability related issues to development organizations to help them design and implement appropriate programs to serve people with disabilities.
- b. Find out reliable facts and statistics on the disability situation in Bangladesh to inform development planners, implementers and services recipients for proper planning and implementation of disability programs through undertaking sample surveys and research on specific disability issues.
- c. Implement integrated development programs and disability programs in selected areas in Bangladesh to facilitate equalization of opportunities for persons with disability in terms of services, benefits, rights and authorities, empowerment and participation in nation building activities or programs.
- d. Develop the skills and abilities of people with disabilities to increase their access to income generation and to facilitate their involvement in income-earning processes.

## **CSID programs:**

**CSID has set down the following programs to reach these objectives:**

- Disability information dissemination
- Pilot programs on community approaches to disability
- Early intervention on problems of children with disabilities in city slums
- Study, research and materials development on disabilities.

# Introduction to the study:

## **Disability in the Bangladesh perspective:**

Bangladesh is considered to be one of the least 'developed' countries in the world as measured in terms of average per capita income, calories consumed per person, high infant mortality rate, and low literacy rate, especially among women. As in most other developing countries, people with disabilities are neglected in Bangladesh too, excluded from or not properly served by most governmental and non-governmental programs. This neglect is compounded by a lack of availability of quality services for people with disabilities to ensure that they can participate in the mainstream development activities. Current statistics indicate that there are more than 12,000,000 persons with disabilities (according to one WHO estimation) living in Bangladesh who currently receive little or no assistance. In too many cases their families and communities leave them out of the general development process. This has resulted in their exclusion from government and NGO programs. This neglect is further compounded by the lack of suitable services to provide assistance to people with disabilities so that they can participate in mainstream development activities.

During the last couple of years, disability as a development issue has been gradually gaining recognition. The United Nations Declaration of the Decade of Disabled Persons (1983-1992) is an example of this. After concluding that the Asia and Pacific regions were behind their target goals at the end of the Decade, another decade was declared for these countries. As a signatory country, Bangladesh is committed to achieving the goal of enabling people with disabilities to achieve equal opportunity so that they can participate in nation building activities.

Many organizations, both governmental and non-governmental, are now considering the inclusion of disability components in their programs. However, disability issues are not very familiar to most development planners and implementers, which is a barrier for many organizations in taking up disability programs. Disability-related organizations themselves do not have adequate information to update their programs and activities to reach the desired quality level. The reasons for this limitation have been identified as a lack of adequate information and supporting documents, and also a lack of easy availability of such materials for development planners and workers. Disability issues – like most development issues – demand a wide range of program coverage, and therefore require a broad spectrum of current and readily available information.

## **Rationale of the study:**

Interventions to provide limited assistance to a few persons with disabilities have long existed in most communities. However, today the lives of most of the people with disabilities in Bangladesh are still influenced by others' ignorance, fear and superstition, resulting in exclusion from normal economic, social, educational and political activities in their families and communities, and a lack of essential services. Ultimately, this societal 'blind spot' may also contribute to the exclusion of impairment and disability as topics in the training curricula of most professionals. The situation of women in Bangladesh calls for improvement. In most spheres of life,

women are discriminated against in favor of men, hindering their full participation in the development process. Women with disabilities are generally in more vulnerable position, facing a 'double disability', first due to being disabled and second for being a woman.

In recent times, development organizations have undertaken extensive programs for the empowerment and development of women in Bangladesh. However, scant efforts have been made to address the problem or issues related to the women and adolescent girls with disabilities, mainly due to a lack of appropriate information for effective designing and implementation of development efforts. Much more research is needed to fill this vacuum of information.

### **Objectives of the study:**

The prime or broad objectives of the study are: "a situation analysis of the socio-economic and psychological status of women and adolescent girls with disabilities of Bangladesh, geared to providing appropriate information to development planners for designing and implementing feasible, effective and need-based development interventions for the women and adolescent girls with disabilities and offer sufficient feedback to the stakeholders."

### **The specific objectives of the study are to assess:**

- Social status and prevailing situation of the selected girls in the families and communities of the study population.
- Status related to (for example): education, health (reproductive), income, employment, family's economic conditions and level of skill.
- Some psychological effects of being disabled under certain social and environmental challenges.
- Psychological and physical changes and environmental factors in the transitional period from girlhood to adolescence.
- Physical and sexual abuses in the family and community.
- Exploration of the meaning of equality and rights.
- Development of possible interventions and scope for assistance for those girls and women with disabilities who require it.

### **Geographical area of the study:**

The study was conducted in twenty-one selected districts of the six Administrative Divisions as shown below (Division-wise):

Dhaka Division	Dhaka, Tangail, Faridpur
Barisal Division	Barisal, Barguna, Bhola
Chittagong Division	Chittagong, Bandarban, Noakhali
Rajshahi Division	Rajshahi, Gaibandha, Serajgonj, Bogra, Dinajpur
Sylhet division	Sylhet, Hobiganj, Sunamganj
Khulna Division	Bagerhat, Satkhira, Jendidah, Chuadanga

**Table-01: Geographical area of the study**

## Methodology:

### Development of tools

A set of objective-based *questionnaire* was developed for data collection in the areas of: personal information, type of disability, causes and treatment, education, family environment and attitudes, participation in family and social activities, decision-making, profession, income and economic contribution to the family, skills, psychological and emotional aspects, scope of treatment for those who require it. The questionnaire was pre-tested and finalized through a review of the test findings.

A set of *guideline* was also developed to provide a standard for the data collectors and supervisors to ensure that data were treated systematically. The guidelines include definitions and clarifications of critical areas of information such as 'transitional period for girls with disabilities' and 'emotional aspects'.

Another guideline was developed to help the practitioners involved in information collection for *case studies*, covering the methods and techniques for getting relevant information and its systematic recording.

The guideline for conducting *focus group discussions* was also prepared to assist those who led these discussions.

### Staff development

A day-long workshop was conducted with a group of twenty five staff from different organizations who had earlier received a three-month long training on disability from the Centre for Disability in Development (CDD). They were selected and engaged as field data collectors. The workshop has focused on the purpose of the study, its methodology and all other technical aspects. Another one-day workshop was held with the supervisors to examine the details of the questionnaire, methods and techniques of data compilation.

### Data collection and compilation

Data was collected from 310 respondents using a pre-designed questionnaire. Of these respondents, 150 were girls and 160 were women with disabilities. The respondents were selected on random basis.

Twenty five selected field level workers collected the primary data, which was further cross-checked and verified by the supervisors to ensure accuracy. The data were then compiled in a tabular and graphic format.

### Case studies

Twenty-four girls ranging in age bracket of 10 to 18 and twenty six women aged from 19 to 60; were individually interviewed for collection of detailed and qualitative information. Trained field workers took the interviews of the respondents and collected the case study from their respective program areas. The selection of

respective interviewees was made considering the distribution of girls and women, the district wise distribution, and incidence of various types and degrees of disability.

### **Focus group discussions and individual conversations**

Four focus group discussions were conducted with community groups with a total of 69 participants. Of these participants, 19 were girls with disabilities, 23 were women with disabilities, 13 were girls without disabilities and 14 were women without disabilities. These discussions were conducted to cover information on sensitive issues such as marriage and family life, reproductive health, birth control, and gender abuses. In addition, individual or one-to-one conversations were held with 20 individual respondents, 12 of whom were women with disabilities and the rest 8 were adolescent girls. This was done mainly to obtain more in-depth information about the participants' emotional and individual perception of and views on critical issues related to their disability.

### **Limitations of the study**

- The study could not measure acute psychological aspects of the consequences or complexities that dominate the mindset of the girls and women with disabilities in an in-depth way through a proper quantitative analysis due to the absence of a standardized tool applicable for people with disabilities in the Bangladeshi context.
- On the one plane the respondents were all beneficiaries of organizations working for the development of disabled persons and on the other the data enumerators were also selected from amongst the employees of those agencies which offered the scope of prior acquaintance between them. As a result there remained the scope of furnishing information (or even hiding them too) on or of mutual interest.
- In some cases, it was not possible to collect information from the participants directly because of communication problem or conservative attitudes. Thus such information collected on the basis of indirect statement of sources other than the respondent provide scope for data manipulation or to be biased.

# Situation Analysis and Need Assessment

## Education:

Education is a crucial area in which women and girls with disabilities are excluded and underserved more than any other group of the society. The lack of social awareness and prevalence of negative attitudes amongst the community people, family members and people concerned with education management are the basic factors contributing to this.

Various educational approaches exist in Bangladesh, such as formal education, non-formal education, and special education. Questionnaire responses indicate that among the girls and women with disabilities who participate in education, most attend formal education using the existing provision of free primary education in the country. Data derived from the questionnaire, individual conversation and previous research indicate that the second highest number of learners attend non-formal education because of the low cost, flexible environment, convenient time, relaxation of age limits, use of appropriate teaching materials/curriculum, and continuous assessment system. These facilities were reported to give the females with disabilities a 'second chance', at education for those who were left or dismissed from formal institutions due to their more rigid structure. Enrolment in special education is much lower because of higher expense and inaccessibility of the programs, as they are mainly urban based. Girls and women with intellectual or multiple disabilities and profound hearing impairments are often placed in special schools.

Disability type-wise, the persons with physical disabilities tend to attend the education institutions more than those with hearing, visual, intellectual and multiple disabilities across the country because it is easier for the former to attend schools. The latter group faced various serious problems with enrollment in education. School authorities often seem to doubt the potential of disabled learners (particularly for the intellectually impaired) to adapt to the existing system and often they refuse to enroll many such learners in both formal and non-formal institutions. The school management even raised objection in enrolling the disabled in the pretext of inadequate policy coverage.

Barriers also exist at home; many parents and family members had no idea that their disabled children/wards could be enrolled in mainstream education.

Data from questionnaire and FGDs indicate that the inaccessibility to educational institutions is a major barrier to education for the girls and women with physical disabilities, particularly in rural situation. During the rainy season it is especially difficult to reach a distant school using inaccessible village roads, and under any circumstances such a commute may be impossibly difficult and/or leave the women and girls vulnerable to harassment.

FGDs revealed that for the hearing-impaired learners noisy classrooms are not a favorable environment, especially for those who use listening devices such as hearing aids. There is no sign language or alternative communication facilities for the hearing or intellectually impaired or those with cerebral palsy or multiple disabilities, many of whom face communication difficulties. There is also problem for visually impaired learners as the Braille materials and books are not easily available at affordable costs.

In educational institution based hostels, girls with disabilities face problems due to the absence of a female house parent. In most cases, the hostel superintendents are male and girls are therefore culturally impeded in sharing any problems of a female or physical nature with them. The overall environment of such educational institutions, whether mainstream or special education; does not favour the disabled learners. It rather stands as a strong barrier for the girls with disabilities to pursue education staying at hostels.

Research findings indicate that family, peers, community people and schoolteachers largely do not favour the education of girls and women with disabilities. In some cases, the difficult environment created by school authorities, teachers, peers or parents of non-disabled students forced the female learners with disabilities to leave their schools. One of the distressing findings is that in addition to teasing by peers and community members, many of the girls had experienced cruel teasing both at home and in the classroom from the teachers themselves. It is really the most humiliating of all. Cooperation from peers in a play environment is apparently marginally better than that of the classroom. However, at times the disabled learners were avoided or neglected as play mates. FGDs revealed that the non-disabled learners sometimes considered their peers with disabilities not to be good playmates.

Many factors shape peoples' negative attitudes towards the education of girls and women with disabilities. Community members, school teachers and administrators do not have enough knowledge on disabilities, and do not receive adequate information about or support for teaching and on provisions to ensuring the full inclusion of the disabled learners.

A remarkable area for consideration is the casual inclusion of the girls and women with disabilities in mainstream education. It happens almost universally regardless the type of disability. It was observed that a good number of disabled girls or women had received education at all levels, including universities or vocational institutes, without any special accommodation meant/arranged for them. This would tend to support the idea that girls and women with disabilities have the potential to succeed in mainstream education, despite the obstacles that they may encounter.

### **Employment situation and Income generation:**

Income generation is a crisis in Bangladesh for both men and women and the situation for females with disabilities is no better. It is beyond the scope of this study to reflect on the ratio of employment for disabled versus non-disabled females, but it is safe to suggest that only a negligible number of women with disabilities are



employed or have access to any income generation options. Those who have access to these activities are often involved through family employment or income generating activities.

The employment environment for females with disabilities is not favourable. When women with disabilities are employed, they often do not get the job-related benefits to which they are equally entitled too. There is a disparity in salaries in comparison with non-disabled employees working in a similar capacity and termination without reason seems to happen quite often.

Individual conversations and the data so gathered revealed that many of the girls and women with disabilities are not treated with due respect in their workplaces. Colleagues sometimes consider them to be an extra-burden. They reported often being teased and blamed with very little excuses. Physically disabled workers face problems due to inaccessible physical environment, and communication problems occurred severely for the hearing impaired workers as others did not 'accept' or understand their non-verbal communication. Difficulties in mobility were reported to be one of the major limitations for the visually impaired workers, due to poorly planned buildings. Interviewees felt that these workplace abuses and disadvantages are the result of negative attitude and non-acceptance of disabled workers in the workplaces.

The limited scope of employment for so many women with disabilities leaves them vulnerable to these sorts of employment problems or workplace hazards. Even a university degree does not ensure employment for the women with disabilities and many were refused because of their mere disability.

On the other hand, data revealed instances of a respectful working environment for some women with disabilities. Employing organizations were fair about the evaluation of job performances of these employees regardless of their disability, treating them as potential contributors and sometimes as more sincere or dedicated and more committed to and firmly determined to succeed despite 'disability'. Evidence of better punctuality of some employees with disabilities was cited in support of this.

The types of income generating activities of the girls and women with disabilities studied are multi-sectoral: official jobs, teaching, small business, day labour, domestic work, handicrafts work, dairy and poultry raising, and sewing to name a few. In most of the cases covered by this research, the women managed the jobs themselves. In other cases, majority of the respondents was left out of any income generating activities.

The incomes of the women and girls studied seems mostly to be spent in meeting the family needs, although their work was not always encouraged by their own family and community.

## Marriage, conjugal relationship and dowry:

The establishment of a romantic relationship ranks very high in one's priorities list for most Bangladeshi people. Although considerable literature in psychological and sociological disciplines examines the dynamics of interpersonal relationships, very little attention has been paid to the effects of disability on those relationships from the woman's perspective. The importance of socialization experiences in adolescence is generally acknowledged, but the fact is that many girls with disabilities have limited access to those experiences due to attitudinal and societal barriers. This study attempted to focus on such factors as attitudes toward the marriage of females with disabilities, how the incidence of disability affects marriage behaviour, the effects of a feminine disability on her partner's behaviour, societal factors, social attitudes and family expectations.

Marriage (generally arranged) is the social norm of most societies. In Bangladesh, the mean age of marriage of women is between 15 and 19 years (UNDP, 1999). The rate of early marriage is generally 48% (Afrin. R. 2000). However, the rate of marriage of adolescent girls with disabilities is 2%. A problem for women with disabilities and their families is that there often remains an apathy among the potential suitors and their families about marrying such a girl. This may be due to the prevailing superstitions that the presence of a disabled person in family will bring misfortune to the whole family. There is also another expectation that the wife will contribute in the household activities physically, financially or both, and the perception is often that a woman's disability would hinder that contribution and instead render her a burden on her new family.

Most of the marriages of the women studied took place against payment of a dowry in cash or kind or land. It was a striking finding that the dowry marriages did not last longer than non-dowry arrangements, possibly suggesting that the marriage was only for the dowry.

Some cases of separations were found after a few years of conjugal life. In such cases, the husband left the wives, taking significant amounts of money without giving any reason. In some cases, husbands demanded more dowry, creating pressure and ultimately leading to separation.

Individual conversations revealed that affluent families often ask their disabled female members not to get married but rather to seek education, believing that they are not capable of being a housewife or taking care of a baby. In some cases, it was found that the family looked for a disabled spouse with whom they could arrange a marriage with their disabled girl. However, this seemed to vary depending on the level of impairment and the type of disability.

Although religious conversion is considered an offence in Bangladeshi society, a different scenario was found when the family of a disabled woman did not react when their disabled daughter converted to another religion to get married. The feeling seemed to be that at least she got married.

Verbal and physical abuse was found to be a common feature of the conjugal environment of the majority of married women with disabilities studied. This abuse happened at the hands of both the husband and other family members. This topic will be further elaborated later in this report.

Acquiring a disability or a marked increase in impairment while involved in a serious relationship can greatly affect the marriage. Some women noted that the relationship suffered when they could no longer be involved in housework, or when they were not in a position to shoulder the required activities of the family. Although their spouses may understand the limitations caused by their disability, they (husband) could not fully resolve the crisis.

When the disability was acquired or worsened after the couple married, most of the women felt that their partner became emotionally distant and less respectful, sometimes discontinuing sexual relation.

Information revealed that women and girls with disabilities in 'overprotective' families were usually discouraged from participating in activities where they could learn and practice social skills. Environmental barriers, such as lack of transportation or access to recreational facilities also created barriers to their participation. Negative attitudes and assumptions of community members about the girls and women with disabilities can act as another barrier in the social arena; a combination of the above factors may also severely limit a female's options when it comes to marriage.

### **Community and family attitudes:**

The overall development of a girl or woman with disability can be greatly affected by the prevailing attitudes of her family, peers, community, educators, and professional colleagues and supervisors. The study confirms that negative attitudes are very much in existence in most of the cases.

Ignorance about the actual causes of disability seemed to be a major factor in shaping these negative attitudes. Some cases reflected that disability has been caused by violence, but the perpetrators remained blame free. It further revealed that the females victims were often blamed for their own disability and it was attributed as punishment for their own bad deeds or behaviour. One reason commonly cited was that the disability often resulted from the girl or woman for not practicing traditional customs and values or other religious sanctions. Parents – most often mothers – are also equally blamed for a daughter's disability on moral ground. In such cases, enforced censure may lead to social isolation.

Disabled children, females in particular, are not treated equally in the family. They are often being deprived of basic needs such as education, food, clothes, health-care and entertainment. Parents do not feel comfortable in investing in their disabled daughters as they are considered as an 'unproductive' member of the family. They are often kept at home to look after household activities, but isolated at the same time; siblings often do not eat or sleep with them, blaming them for sharing their misfortune with the rest of the family. This blame, misunderstanding and separation

can also create problems when it is time for a marriage to be arranged for the ill-fated girls or someone else of the family.

Although some girls and women with disabilities are engaged in income generating activities, they are not recognized or rewarded for their contribution to the family economy. Some are recognized in the family and in that case they get due share of the property from their parents. In many cases, the girls or women studied did not have access to family decision-making, even when it pertained to their own children.

On the other hand, some families were found to be very supportive of their disabled members. Some parents were willing to make considerable sacrifices in order to ensure their disabled daughters' education, such as leaving a government job in order to migrate to be nearer to their daughters' educational institution. The result of this type of support from family or community seemed to be an inducement to increase the feeling of confidence or success, whereas negative attitudes contribute to generate feelings of depression, low self-esteem, and dependency.

### **Abuse:**

There has been a wealth of research in Bangladesh on domestic violence and sexual assault against women, although it is incomplete in that it almost never incorporates a disability perspective or information. A few studies have focused at the situation of women with disabilities (as related to abuse) in global aspects.

Abuse may be defined for the purposes of this study as:

- 1). **Emotional abuse:** *being threatened, terrorized, or verbally assaulted,*
- 2). **Physical abuse** : *any form of violence, and*
- 3). **Sexual abuse** : *being forced, threatened, or deceived into sexual activities or even rape.*

Women with disabilities appear to be at risk for emotional, physical, and sexual abuse. The prevalence of abuses of the girls and women with disabilities was found to be at high side (92%) for both. Cases of emotional abuses (78% and 75%) also seem at high side and at near equal frequency for both category. The scenario also appeared similar in the cases of emotional abuse (82% for both) and sexual abuse (32% and 37%).

In many cases, even the parents abused the girls and women. Neighbours and community people were the next most common abusers in the categories of emotional and physical abuses. Husbands' abuse of their wives was found to be common except in a very few cases.

Interrelationships were observed between the type of disability and sexual abuse. Most cases of sexual abuses were reported among the females with intellectual disabilities. The findings also indicate that these girls and women did not understand the meaning and consequences of sexual abuse, and could not explain the incidences to anyone in detail. The second most frequently sexually abused group was girls and women with hearing impairments. The vulnerability here appears to be

the females' incapacitation to effectively establish communication with others. Visually impaired females are also vulnerable to this type of abuse. It was even found that a traditional healer took sexual advantage of the situation from the girls and women with disabilities, especially in cases of intellectual or visual impaired ones in the name of treatment.

Sexual abuse was reported to be often experienced by women with disabilities by those family members or neighbours who were ostensibly helping them, such as with mobility. Parents, even knowing or identifying that their daughter had been sexually abused, did not want to take any action because of the tendency in society to blame the victims rather than the criminals.

Girls and women with disabilities were more likely to experience emotional abuse by family members, attendants who look after them, strangers, peers and even sometimes by school teachers. One common form of this type of abuse, for example, is to refer to the girl or woman by the type of her disability, rather than by her real name.

Physical abuses such as beating, hitting, physical punishment, and deprivation from food were reported as the most common type of abuses. Within families, grandmothers seemed to be more sympathetic to the victims or less likely to abuse the girls than their parents.

### **Reproductive health:**

Reproductive health is a crucial and sensitive issue in Bangladesh. Most of the girls or women studied were not clearly aware of the issues related to the physiological changes that the human body undergoes or phases of reproductive health. Disabilities were also found to cause concern as they carry the danger of a possible risk or complication during pregnancy.

The conservative nature of Bangladeshi society is not conducive to discussing reproductive health issues. Parents often do not speak about reproductive matters to their daughters, and thus adolescent girls often get their first information or ideas about reproduction and the phases of physical development from peers, elder sisters, sister-in-laws, and grandmothers. A majority of the girls covered by the study had serious problem with shock, intense fear, depression, and embarrassment when faced with first menstrual period. Communication impairments such as speech and hearing difficulties seemed to contribute more intensely to this problem during this phase of physical change because of the difficulty in sharing experiences or communicate their problems with others who can be of any help or extend support. In some cases, teachers in special schools helped the girls enrolled to understand the situation and offered support. Case studies indicated that those girls with intellectual or multiple disabilities had greater difficulty; it was reportedly problematic to teach them to take care of their menstruation. Very few girls and women respondents were informed about the safety or convenience of various birth control methods. Some were well aware of contraceptive methods, but did not consider them 'user friendly'.

## **Natural physical growth:**

Puberty is a normal development process in the human body due to hormonal changes. No human being in a sound health can avoid this change. During this change naturally some physical demands take place. Case studies indicated that those girls and women with multiple or intellectual disabilities covered by this research have difficulty, in most of the cases, understanding the meaning of changes caused by puberty. Some cases of hearing-impaired girls or women indicated that they have insufficient knowledge about these issues due to inadequate social interaction or lack of sharing experiences due to their difficulty in communicating with knowledgeable one. Visually and physically impaired girls and women studied fared better in understanding and handling the changes that their bodies went through, although they faced challenges in dealing with or managing them physically. They rather experienced problems in managing the change due to their limitations.

Along with the physical changes brought on by puberty, changes in behaviour tend to occur. In the case of some females with intellectual disabilities studied, their families did not accept such physical changes positively and became worried, restricting the girls' free movement to hide their physical growth. There were even instances of reducing the girl's quantity of food to halt puberty-related growth by the family. However, such extreme cases are rare. But the central tendency of the data support the notion that the respondents have very little or no knowledge of such developmental changes and hence face problems.

## **Psychological phenomena:**

This part of the study mainly tried to focus on the emotion and feelings of the adolescent girls and women with disabilities for being disabled, and how do they react to different social conditions. The psychological development of the girls and women with disabilities, like others, depends to some extent on emotional, environmental and social factors such as self-assessment, peer acceptance, family and social attitudes towards them or vice-versa, and even isolation, among many others. The problems that the people with disabilities often face in terms of familial and societal acceptance and support for their special needs can contribute negatively to their psychological state, leading to depression, frustration and a feeling of isolation. One-to-one conversations revealed that many of the women and girls felt a lack of affection at the family level, leading to loss of self-esteem and development of a feeling of their potential being destroyed. Some positive dynamism in the family is especially important here; both neglect and over-protectiveness may lead to development of a feeling of low self-esteem or even depression. Segregation from society and family was a common feature for the girls and women with disabilities in many cases.

Data derived from individual conversations and FGDs indicate that sexual abuse had created such a psychologically stressful situation for some of the girls and women with disabilities that they could not even express their situation to anyone and could therefore seek no recourse.

FGDs revealed that in most cases the girls and women studied were deprived of their basic human 'needs' and rights such as food, education, health-care and minimum social respect. Consequently, maladaptive behaviours such as aggressiveness, destructiveness, paranoia, and absence from work developed in them, and subsequently those become a part of their everyday personal and working lives.

On the other hand, it was observed that some girls and women with disabilities got proper and positive acceptance from the family, society, educational institutions, work places and others concerned. These cases show a clear difference in terms of positive psychological development as opposed to those discussed above. These favourable background or friendly-environment immensely helped the respondents to attain success in family and personal life as well as in education, professional life and nation building.

### **Human rights issues:**

The most important issue of human rights is the security of human life. This has been violated in many situations related to the girls and women with disabilities studied. This research reflects that many were sexually abused, physically tortured, verbally abused or became disabled due to violence, among other things. These human rights violations went unpunished; paradoxically the victims were often themselves blamed.

The girls and women with disabilities studied were generally deprived of access to treatment and health facilities due to social beliefs and superstitions and they were given treatment from traditional or religious healers or no treatment at all. They have also been deprived of the rights to basic education, as in cases where school authorities refused to enroll them; this is in violation of the right of everyone's to education as defined in the Declaration of Education for All and the national disability policy.

Communication may be considered a basic right, but there is no recognized communication device for speech and hearing impaired persons in Bangladesh.

### **Ability, dignity and self-esteem of the respondents:**

Data obtained through questionnaires, interviews and one-to-one conversations revealed that a majority of the girls and women with disabilities (including 'severe' degrees of disability) have confidence that they should be educated and engaged in gainful (economically) activities and offered opportunities in contributing to nation building endeavours. Many of them are skilled in trades such as sewing, cooking, painting, handicrafts, tailoring, dairy and poultry raising. It was observed that further training will enable them to be more involved in multi-sectoral areas of income earning. There are successful examples of micro-entrepreneurship such as managing grocery shops, handicrafts production, and dairy and poultry rearing. Some of the women were employed in formal organizations and assigned to official jobs. These examples evidently prove that the adolescent girls and women with

disabilities have the potential capabilities to establish themselves as productive members of the society, if proper chances and appropriate and effective enabling environment are provided. These achievements also help to boost up the feeling of dignity of the girls and women with disabilities. FGDs revealed that a woman's opinion is considered with more value in cases where she is a money earning member or economically self-sustaining.

One of the most significant findings of the study is that some of the women with disabilities established themselves as a recognized contributing member of their family and society overcoming all environmental barriers. There is also evidence of extraordinary achievement by severely disabled women. However, this is a reflection on the level of self-esteem and determination. The influence of access to education and a positive working environment has resulted in such recognition.

Case studies show that in some cases the girls and women with disabilities who had access to employment established normal romantic relationship with the man of choice and are living a happy married life. They have never experienced physical or sexual abuse(s), enjoy a positive family-environment with good attitudes of respect from their inmates, and demonstrate high level of self-confidence.

The study revealed no relationship between self-esteem and type of disability, suggesting that the self-esteem of the girls and women studied is more strongly influenced by social and environmental factors.



# Fact Analysis

## General Information:

A total of 310 respondents were interviewed applying separate set of duly pre-tested questionnaire. Out of these, 150 were adolescent girls and the rest 160 were women. This chapter analyzes the compiled data so obtained. Data have been analyzed independently. However, although when the data are on similar ground a comparative or summative analysis has also been done.

## Age groupings:

For the purposes of this study, adolescence period was considered to be between the ages of 10 and 18. Out 150 respondents 81 (54%) were in the age group of 10 to 14. The remaining 69 (46%) were in the age bracket of 15 to 18. Independently the 11-year olds numbered the highest at 26 (17.33%), followed by 15-year olds at 24 (16%).

The legal age of maturity of 18 years old was the baseline for womanhood. In the women's group, out of 160, the highest percentage falls in the age group of 19 to 25 at 38.75% (62) . When the age was taken independently, the highest figure was found at 30 years, numbering 20 (12.50%), followed by 20 years, numbering 19 (11.88%).

## Members per family:

In the adolescent group, the families with members between 6 to 10 numbered highest at 80 (53.33%). This was followed by 65 families with members in between 1 to 5 (43.33%).

This trend is not seen in the women's group. In this group the families with members between 1 to 5 numbered 83 (51.88%) is the highest. The second highest group is in between 6 to 10 members, numbering 70 (43.75%).

**Table 42: Members per family**

Family Members	AWD	WWD	Combined
1~5	43.33%	51.88%	47.74%
6~10	53.33%	43.75%	48.39%
11~15	2.67%	4.38%	3.55%
16 & >	0.67%	0.00%	0.32%

Among other factors, the number of family members in a family exerts direct influence on the situation of a person with disability. Depending on the severity of the disability, a person with a disability may require daily care and assistance to perform the activities of daily living. A person with disability residing in a family should naturally receive such support from one or more members of the family. Regular provision of such care requires time, and time equals money. For a family with few members and economic hardship, it is at times very difficult to provide the service and care to its disabled members. If one member is engaged for providing continuous care, it causes economic loss for that individual at the personal level as well as family level. It is normally seen that it is a female member who looks after

the disabled member. This may prevent her (the attendant) from attaining education or participating in other development and social activities as she needs to stay at home. For a larger family, it is more possible to share the care-time required for the disabled member.

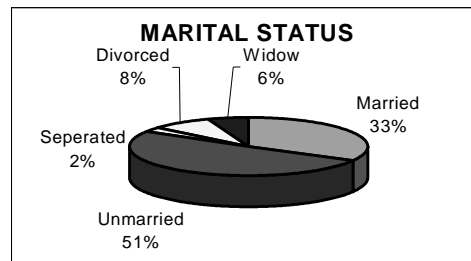
**Profession of the family head:**

In both the groups the main profession of the head of the families of the girls and women with disabilities is business. In the adolescents and women’s group it is 30% and 26.88% respectively. The second highest profession practiced is farming at 18% and 16.88% respectively. 15.33% in the adolescents group and 17.50% in women’s group are jobholders. Except for 1.25% in the women’s group none reported of having Government jobs.

**Marital status:**

It is not uncommon to have cases of underage marriage in Bangladesh, especially in rural areas. However, according to the compiled data of the adolescent group, only 2% reported being married.

In the women’s group, only 33.13% reported being married. 8.13% are divorces. The majority (50.63%) still unmarried.



**Figure-12: Marital Status**

Marriages are still primarily arranged in Bangladesh. In the villages and semi-urban areas a trend can be seen of getting daughters married at an early age; most girls get married by their mid-twenties.

The figures from the interviews indicate that disability is a strong barrier to marriages and ongoing relationships. Findings show that disability is an important factor in respect of marriage, including separation and divorce.

**Types and degrees of disability:**

The gravity of disability by types among the girls with disabilities and women with disabilities was broadly the same. The major group had physical disabilities, 37.33% among adolescents, and 40% among women. Speech, hearing, visual and intellectual impairments follow next. Multiple disabilities were seen in 10% cases. One reason for the higher percentage of physical disability prevalence might be the higher visibility of physically disabled in comparison to other types of disability.

**Table: 23- Type3 Type of disability**

Disability	AWD	WWD	Combined
Physical	37.33%	40.00%	38.71%
Speech & Hearing	21.33%	19.38%	20.32%
Visual	16.00%	16.88%	16.45%
Intellectual	14.67%	14.38%	14.52%
Multiple	10.77%	10.36%	10%

physically disabled in comparison to other types of disability.

In the compiled figures on degree of disability, the highest figure was seen in moderate group at 36.13%. The lowest was in profound at 9.35%. While making comparison between the two groups, it is an interesting point to note that at severe category, the prevalence rate in percentage among the girls with disability than that of the women with disability is notable. A reason for this could be that

**Table: 34 Degrees of disability**

Degree	AWD	WWD	Combined
Mild	25.33%	23.75%	24.52%
Moderate	43.33%	29.38%	36.13%
Severe	20.00%	39.38%	30.00%
Profound	11.33%	7.50%	9.35%

due to lack of proper care and services, a steady deterioration of the state of disability occurs for girls and women with the passage of time. Another reason, as it was observed, could be that disability occurring at an older age had resulted in a more severe impairment.

### Causes of impairment resulting in disability:

Data reflect that the major causes of impairments are congenital, high fever and diseases.

A majority of these causes are preventable. But due to lack of awareness, proper information, and practices, impairments occur even through they are avoidable or preventable. This calls for a massive improvement in primary health care services and practice, especially in mother and child health care services. An alarming 41.94% of impairments leading to disabilities are due to congenital ifactors, highlighting the need for better prenatal care. 3.23% of disabilities occur as an after effect of improper or mal-treatment. This portrays a sorry picture of the health care system and health knowledge at the grassroots community level.

**Table 5 Causes of disability**

*(Responses are higher than the number, as a respondent may have thought of more than one cause)*

Cause	AWD	WWD	Combined
Congenital	45.33%	38.75%	41.94%
Diseases	14.00%	23.75%	19.03%
Fever	23.33%	20.63%	21.94%
Burn	0.00%	1.25%	0.65%
Accident	8.00%	5.00%	6.45%
Wrong Treatment	2.00%	4.38%	3.23%
Malnutrition	0.67%	1.88%	1.29%
Unknown	6.67%	1.88%	4.19%
Others	0.00%	2.50%	1.29%

**Table 45 Causes of Disability**

### Places of treatment received:

Data reflect that 93.33% of girls with disabilities and 97.50% of women with disabilities have in some stages of their lives received some kind of treatment for their disability, suggesting that families have the desire to seek treatment for their disabled members.

However, data revealed that most people interpret disability as a disease and initially believe a cure also exists. As it becomes gradually clearer that a cure is not possible, many families lose hope and become hopeless and refrain from seeking further essential health-care services for girls and women with disabilities. This is mostly due to lack of information and awareness as well as economic incapacitation. Individual one-to-one discussions revealed that the ignorance of families about

disability related issues may, at times, leave them vulnerable to exploitation by some so-called traditional healers. It was observed in many cases that the families had incurred a huge amount of their hard-earned income on false cures only to be disillusioned. Thus, the families ultimately withdrew supports and neglected the vitally needed medical interventions or treatment need for the victims.

**Table: 56 - Source of treatment**

Place	AWD	WWD	Combined
Hospital	30.67%	34.38%	32.58%
Clinic	5.33%	6.25%	5.84%
Private Doctor	51.33%	35.00%	42.90%
Village Doctor	29.33%	31.88%	30.65%
Traditional Healer	30.67%	27.50%	29.03%
Religious Healer	34.00%	34.38%	34.19%
Field Worker	7.33%	8.75%	8.06%
Paramedics	0.67%	1.25%	0.97%
Others	1.33%	1.88%	1.61%

(Responses are higher than the number, as a respondent may have received one or more of the above treatments)

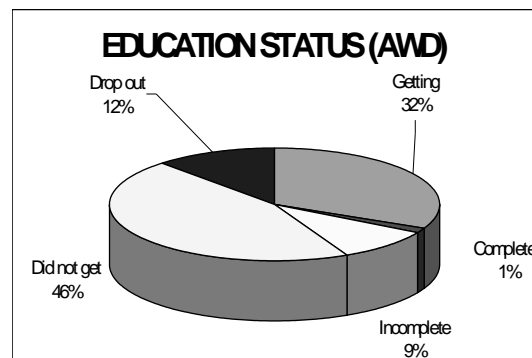
The families of the respondents have sought treatment from a varied range of sources. The most frequently approached source was private doctors. This trend has increased with time. In the girls with disability group as much as 51.33 percent cases have used this option. In conformity with the socially prevailing notion, it is interesting to note that in 34.19% and 29.03% cases the families of the victims had sought treatment from the religious and traditional healers respectively.

Data supported that most families are ready to bore treatment expenses. In reality they paid 89% of the treatment costs. Besides the families, the government, development organizations, and community people also contributed but their combined share is below 5%. This is due to fact of not bearing the treatment-costs from the government for the people with disabilities. Family members who spent a huge amount of time, labour, and money scavenging for a 'magical cure to disability' are seldom left with further resource to cover costs of advanced but costly treatment for their disabled member(s). These different types of treatment efforts were not always without positive results.

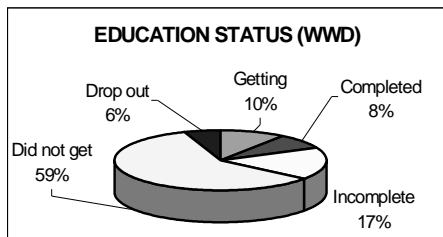
Reports indicate that for 5% of the girls and women with disabilities measurable improvements were recorded, while 26% reported negligible improvements; for 68% no change was recorded or possible.

### Education status:

Disability is a barrier to education. But the problems related to attitude, accessibility to existing facilities/options and awareness level of others also act as barriers for the education of the girls and women with disabilities. In the cases of the women and girls with disabilities only a limited few that were included into the mainstream education, a huge percentage dropped out due to teasing and problems associated to disability



**Figure-23: Education Status of AWD**



**Figure-34: Education Status of WWD**

training that could offer her an option in the job market. It is either formal education or no education.

The highest enrollment can be seen in the primary school at 21.25% for women with disabilities and 30.67% for girls with disabilities. A massive 64% (average figures of girls with disabilities and women with disabilities combined) drop-out rate occurs at primary to secondary stage. This trend also continues in their transition to further education. The study did not have much scope to find out the reasons for such high rate of drop-out. It demands further in-depth study on this particular issue alone. Just as education is imperative for a nation to develop, it is also imperative to ensure education for the girls and women with disabilities. "Education for All" becomes meaningful slogan only when it addresses all target groups and citizens of the nation.

36.06% of the women with disabilities and 36.58% of the girls with disabilities were either teased or their ventures to study were not supported (not in favour) by other members of their surrounding environment. The highest disregard came from their peer groups (50% reported of being teased or situation not being in favour).

On an average 9% of the women with disabilities and girls with disabilities reported that they received general help from all sectors, the highest being from the other members of their families.

### Participation in family, social and other activities:

It was recorded that only 7.10% participated in games and sports. A larger, yet still negligible, 26.13% respondents participated in social activities. Several reasons for this low percentage were mentioned by the women with disabilities and the girls with disabilities. These were: 'many family members did not take the effort to involve them', 'they were too shy due to their disability and

resulting from not disability- friendly but inaccessible environment. The enrollment rate among the girls with disabilities is much higher than it was for the women with disabilities, but still it is negligible. At the same time the rate of dropout in the process of continuing education is alarming. Only 3.75% have proceeded on to university education in the woman with disability group. Another alarming finding is that virtually no one has received any skill

**Table: 67 Education Status**

Options	AWD	WWD
Getting	32%	10%
Completed	1%	8%
Incomplete	9%	17%
Drop out	12%	6%
Did not get	46%	59%

**Table: 78 Always Level of participates participation in family, social and other activities**

Activities	AWD	WWD	Combined
Social functions	26.67%	25.63%	26.13%
Visiting relatives	30.00%	21.88%	25.81%
Watching T-V-, cinema, theatre	31.33%	33.75%	32.58%
Cultural activities	10.00%	6.25%	8.06%
Games and sports	11.33%	3.13%	7.10%

(Responses are higher than the number, as a respondent may have participated in more than one activity)

refrained from participating', 'they were being teased or people were staring at them which made them uncomfortable', 'their problems associated with their disability prevented them from participating', etc. Even though figures state that actual participation is low by women with disabilities and girls with disabilities, but in terms of their intention to participate, the response is satisfactorily high. 53.5% reported

**Table:9 8 Never participates in family, social and other activities**

Activities	AWD	WWD	Combined
Social functions	13.33%	18.13%	15.81%
Visiting relatives	15.33%	15.63%	15.48%
Watching T.V., cinema, theatre	13.33%	18.13%	15.81%
Cultural activities	40.00%	52.50%	46.45%
Games and sports	41.33%	81.88%	62.26%

(Responses are higher than the number, as a respondent may have participated in more than one activity)

that they were interested to participate, while only 7.5% commented that they would never like to participate.

There is no denial of the fact that many problems are associated with disability. But at the same time there are solutions too. A little awareness, willingness and certain interventions combined together can change such situations. The role of the family members is extremely important in preparing a disabled member to be able to participate in with

the activities and affairs of the family and society. The society must also have the attitude and willingness to acknowledge the capacities of a person with disability and recognize him / her as an useful member of the society. This positive intention must be supplemented with the opportunity of accessibility. A building (for example a cinema hall) with inaccessibility features cannot be used by a person with disability. A simple ramp will allow accessibility to the people with disabilities with physical impairments. Accessibility should not be limited with physical infrastructures only. It must also be ensured in all policy matters. Rehabilitation interventions also play an important role in developing the capacities of the girls and women with disabilities to enable them to join in the mainstream activities of the society.

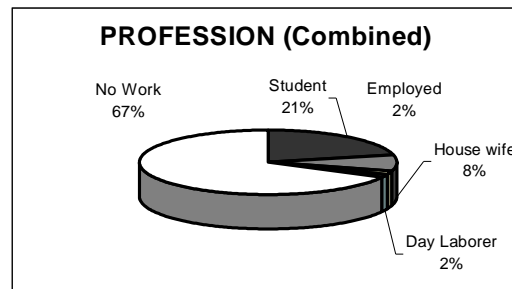
### **Social relationship:**

Efforts were taken to focus on the status of relationship of the women and girls with disabilities with their male counter parts and also with non-disable persons. It was revealed that in both the groups about half had average relationship with people with disabilities and or no-disabilities. It was however interesting to note that in the women with disabilities group 21.88% reported that they had very intimate relationships with other people with disabilities, but in the case of girls with disabilities it was only 6.67%.

Most girls and women with disabilities are still staying at home, away from mainstream society. Societal gender discrimination only worsens this situation. This withdrawal allows little or no scope for the girls and women with disabilities to develop relationship with other members of the society. For relationships to develop and persist with mutual respect it is essential to understand each other. But unless contacts are established, relationships will not develop. Limited contacts on the other hand may lead to relationships that are not strong. More contacts with people with disabilities will also help to change the negative attitude of the community.

## Profession of the respondents:

It was discouraging to note that hardly any participants (3.21%) from the two groups were involved in full time income generating avocations. 64.52% had no paid work. However, some of them, especially the women with disabilities (21.88%) were still earning something through various activities. However, in most cases the earning is less than Taka 500 per month. Only three respondents were earning between Taka 1000 and



**Figure-54: Profession of the Respondents**

3000 per month. Most of them were engaged in handicrafts. Sewing was also a preferred profession.

**Table: 10\_9 Profession of the respondents**

Profession	AWD	WWD
Student	32.00%	10.00%
Housewife	0.00%	15.00%
Employed	0.67%	2.50%
Day Laborer	0.00%	3.13%
No Work	65.33%	63.75%

81.33% of the expenses of the girls with disabilities were mainly borne by parents (father and mother together or independently). Brothers came second at 7.33%. In the women with disabilities group parents met 42.39% of the

expenses as most of them lived in their parent's house without any work. For 23.18% of the women with disabilities expenses were borne by their husbands. The expense coverage by brothers for this group was 17.88%. Ageing or death(s) of parents become a constraint to the financial support for the victim children/wards because in the former event the parents can hardly extend support and in the second scenario the question become redundant.

An interesting comparison can be made with the expenses covered by husbands. Even though 33.13% of the women with disabilities are married, their husbands supporting only 23.18% of them. That is, at least in 10% cases; the husbands are either unwilling or unable to incur these expenses or expect that parents of the women would bear these expenses. This happens due to the negative acceptance by the husbands or in-laws in most of the cases. It was found in individual conversations that the husbands think it is enough for them to marry a disabled woman and it is the duty of parents of that woman to bear all expenses of their daughter(s).

## Training for Professional development:

In the girls with disabilities group 21.33% requested for arranging training for professional skill development and 20.63% of the women also requested it. The most sought for trainings in the girls with disabilities group were further education (28.13%), sewing (25%), handicrafts (18.75%). The women with disabilities requested for: handicrafts (24.24%), sewing (15.15%), and poultry (15.15%).

The importance of a family member in a family and his/her role in decision-making process depends largely on his/her capacity to contribute towards the needs and requirements of the family, especially in terms of monetary contribution. For an individual to be economically independent and be contributive depends on different factors like possessing proper skills, investment capability, having jobs, etc. Access to economic initiatives and the job market is comparatively more limited and almost difficult for women and it is more so for women with disabilities. If their skills can further be developed then their level of confidence will boost-up and they will have more possibilities to be included in the job market. Once involved with income their dependency on others for survival will also reduce. Their productivity will in one way or another contribute to the national development

## **Further Research Suggestions**

- The findings of the study indicate the demand for further research on issues related to the educational phenomenon of girls and women with disabilities. The issues primarily are: assessment of the present educational opportunities and their effectiveness, reason of drop out or incompleteness of education or the reason behind totally being out of education etc.
- Another area of research is on the scope of rehabilitation for the girls and women with disabilities
- Research can also be carried out to explore the potentials and skills of girls and women with disabilities and to find out the employment opportunities for the girls and women with disabilities.
- On the basis of findings, a research on the conditions of human rights issues of girls and women with disabilities and identifying the violation of such rights can be done.
- An in-depth anthropological research can be conducted on physical growth, reproductive health and married life of girls and women with disabilities.
- For further research a standardized attitude scale can be used for measuring the attitudes of family, society, school, peers etc. towards girls and women with disabilities.

## **The Feminine Dimension**



|

of Disability

**Fifty tales of girls and women with disabilities**

## Case study - 01

### Namita Halder: Acid-terrorism defaced her Portrait of life

Namita Halder, 32, is a smart and pleasant young lady. When Namita was a student of class nine, she became an ill-fated victim of acid-terrorism. She is an example of crude hatred out of family animosity. The acid razed through her soft skin burning and disfiguring her body and face. *"... I could smell my skin burning, the pain was excruciating, I felt as if sharp knives were cutting my flesh, my eyes were feeling like being roasted in flames of fire, I was scared, very scared, I could see nothing, it was all dark and pitch black"*— said Namita in choked voices and tears even after so many years while remembering her saddest past.

**Following the acid-burn Namita was immediately rushed to Khulna Sadar Hospital. Little could be achieved there. The quest for treatment, however, did not end. From Khulna she was first shifted to IPGMR Hospital, Dhaka, but it was already too late for the doctors there to offer any significant relief. Her family members then took her to Pongu (Orthopedics) Hospital, Dhaka where plastic surgery was done but without any improvement. After that she was taken to Chandroghona Christian Hospital where some attending foreign doctors treated her hands. As some improvements were marked she was sent to Spain for advanced treatment with a group of acid victims. In Spain further plastic surgery was conducted but her wounds were so deep that no significant improvement could be achieved. She returned home with dissatisfaction, if not disillusionment.**

*...With the time passing out Namita discovered that link with her family members was gradually decreasing. Her relatives pay her a visit irregularly; she too very seldom visits her native home. It is not that her heart does not desire to go but she does not want anymore to face the different attitude of the people of her village. She no longer wants to hear any comments that will give her pain...*

**The treatments offered to Nomita were very expensive. The family had no choice but to sell their land and house to arrange money to incur the treatment costs. *"...she is my daughter, and I will go to the last of my capacity to help her"*- said her father. But it seemed to the family that they were running after a magical cure for Namita, a cure that is impossible to attain. Namita became disheartened and so the family members who cried in silence for their inability to help Nomita any further. Coincidentally, during that time of despair the family met with a Father of a foreign missionary in Khulna. He was deeply shocked and moved at the heart rendering pitiful condition of Namita and her family. He expressed his willingness to help her.**

**The Father arranged advanced treatment for Namita. It resulted in some improvement. The Father then took Namita to Baptist Sangha School for Blind Girls in Dhaka. She started to stay there. She was alone, faraway from home for the first time. She became homesick in the initial days, but gradually adjusted with the new life. At this School she began to receive vocational training. Soon she was admitted to Class IX at the integrated educational setup at Ideal School in Mirpur. This offered her a new life. She was filled with joy. Namita started to dream of a better future again. She stayed at the hostel of Baptist Sangha and completed her matriculation from Ideal School. With her confidence back, Namita felt recharged with a lot more determination and self-esteem. With the passage of time she successfully completed the different levels of education, and ultimately obtain the most coveted Graduation Degree.**

**After her graduation, she joined the Baptist Sangha School for Blind Girls as an assistant teacher. She became very happy with her job. This job has made her self-**

dependent. A monthly income of Taka 3,100 that she earns as a teacher is considered good enough for her independent livelihood.

At work, Namita's colleagues help her a lot. But every morning she is reminded of her disability when she needs to seek help in signing the attendance book or when she needs to do simple things that she cannot do alone because of her disability related incapacitation. *"...if only there was some way that I could do these things independently"*, she exclaimed; that would mean more liberty of life & living.

With the time passing out, Namita realized that link with her family members were gradually decreasing. Her relatives now visit her irregularly; she too very seldom visits her native home. It is not that her heart does not desire to go but she does not want anymore to face the rather indifferent attitude of the people of her village. She no longer wants to hear any comments that will give her pain. *"...I am, what I am, my present incapacitation is not of my own choice, but people don't understand or take the simple facts of reality to comprehend my feelings"*— said Namita in tears.

Separation from her family gives her great pain. She finds it very difficult. She, once a very family-type girl, who could hardly remain away even for a short time from the warmth of her loving mother and caring father, is now far away from them for longer times. At times, when she is lonely, she contemplates with warm tears flowing over her face.

The criminals who caused these damages to the life of Namita were eventually arrested and punished for lifetime imprisonment by court of law. People said, *"...justice was done"*, but to Namita's father it made little difference. *".... Will it bring backlight to the eyes of my daughter? Will others treat her better? Will she have the same opportunities and scopes? Will she be married and have a family?"* asked the father.

Marriage is not in the mind of Namita; she has no such dream. She just wants to pass on her days in the world without much expectation. She at times questions about her very presence in this world. She often asks – *why had it to be like this for her? What harm had she done that such violence was inflicted upon her? Why had her future been shattered? Whenever she feels deep despair and pain with such thoughts, or digs even casually into the horrific memories of the dreadful events of her past, or thinks over the fears of unknown uncertainty the future beholds for her, She feels like a lost one in despair. But she immediately conjures up strength from the responsibility she currently holds of in imparting education to the blind girls. She now has friends, a place to stay and a means of living; this gives her courage and fresh inspiration for a new life. Even in untold sadness, she thinks life is still worth living – it is not totally lost.*

### Case study - 02

Lovely \*: A girl who has realistic dreams

Lovely, 19, is the daughter of a poor farmer from Barisal. She is a case of severe visual impairment. At the age of five, Lovely had typhoid. Initially the village doctor treated her. But as her fever did not subside, she was taken to the Barisal Medical College Hospital for treatment. High fever and maltreatment had already taken their

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\* Actual name has been concealed due to personal request

tolls. Lovely had in the meantime lost her vision to some extent. It took long ten days in the hospital to bring her fever under control. With regard to her resultant visual impairments, the parents were told that no additional treatment could be done at that time, and they would have to wait till Lovely is grown up in due course.

As Lovely's parents were very poor, they could not take her to professional doctors for proper and effective treatment. Instead, when Lovely reached her teens, they took her to a village religious healer. It is unfortunate that the healer used to sexually abuse Lovely in isolation in his room in the name of treatment. Lovely often cried and refused to go there any more. The parents were confused and soon lost interest to seek any sort of treatment for Lovely.

*...On of the major barriers that Shahna experiences is that her hostel house parent is a male. This prevents the girls living there to share their personal problems, especially problems related to their adolescence...*

From her childhood Lovely was keenly interested for education. To make her dreams real, Lovely was enrolled in Class IV in to the Government Blind School in Barisal. She stayed in the residential hostel of the school. Ever since she had left home, she had not returned to her native home to her family. At times her father paid her visits. Cost of her education is borne by the school. Lovely feels frustrated at the fact that the 64 Integrated Blind Schools run by the Government are open only for the boys. This discrimination is denying many visually impaired girls of the obtaining right of education. Besides the general schools are not interested to enroll visually impaired students of either sex. Even if they are enrolled they encounter many problems. For example, during the examinations they seldom get the additional assistance that they require, the teachers also get aAnitated if they are too often approached for such assistance.

Lovely herself has faced many challenges in her journey to pursuing education. Accessibility features and road safety have always been problems for her. She always needed assistance in crossing a road that falls in between her hostel to the school. The school attendant (so called Aya) always used to help her to cross the road. Once, on the day of her mathematics examination the Aya failed to turn up. Lovely became worried and started to cry fearing that she will not be able to sit for her examination. The hostel house parents, however, realizing the urgency of the situation; called for a rickshaw to take Lovely to school. Lovely started for her school by rickshaw but unfortunately on the way it met an accident and as a result Lovely could not appear in the examination. This is just one of the many obstacles that Lovely has to encounter in her struggle to build her career.

One of the major barriers that Lovely experiences are that her hostel house parent is a male. This prevents the residing hostel inmates (female) to share their personal problems, especially problems related to their adolescence growth and reproductive health.

Attending social and cultural programs is also a problem. Ever since the girls of the hostel have grown up they are virtually not allowed to go out of the hostel premises. They however try to participate in the different events of the National and International Days for the persons with disabilities

Lovely is determined to complete her education despite the obstacles and barriers that may come up in course of the events. Alike all other visually impaired persons

Lovely also wants the assurance of employment – the way to be independent in life at least financially.

The dreams of Lovely are not big but realistic. She would like to complete her studies successfully first, then get a job, become self-reliant and at the same time contribute to her family and reduce the burden of her aging father. But she is uncertain if her dreams will ever come true.

### **Case study - 03**

Ayesha wants answer to her unanswered vital questions

**Ayesha, 45, is an intellectually disabled girl. Her father is a retired village school teacher. She is the only daughter in a family of six children. She had severe seizures ten days after her birth. The financial insolvency and lack of awareness of her parents prevented them to seek experts' consultation and appropriate treatment for the girl. The family thought no harm would occur to Ayesha. But with the passage of time they realized how wrong they were.**

Ayesha is not the only disabled member of the family. She has two more brothers who are also victims of intellectual disability and hearing and speech impairment respectively. After the retirement of her father Ayesha's eldest brother was the only earning member of the family. But sadly he too met a road accident and lost his leg.

*...In a few years time Ayesha will be of marriageable age. She dreams that one day she will get married and have a family. But her family is not so positive. It is already very difficult for a woman of a poverty-stricken family*

However, the family was not totally indifferent to Ayesha. When she was of school going age her elder brother enrolled her in a school. They had the expectation that by cross mixing with others Ayesha's behavioral problems would be normalized. It was very difficult to convince the school authorities to enroll her. The teachers of the school had no professional training in teaching children with disabilities, particularly the intellectually disabled ones. As she was different from others, the peers neglected and teased her in the school. She was not learning in the school and was feeling isolated and unsecured too. Soon she discontinued to attend the school.

**The family is currently in severe economic crisis. The elder brother after losing his leg stays at home and naturally he has no income. The family has to live on whatever little cultivable land they possess. They were not able to provide any sort of professional support to Ayesha to improve her condition.**

Ayesha tries to help in the household activities. But there is little that she can do or help. The family at times complains that she is both lazy and stubborn. She is now quite neglected by her family. She is not allowed to participate in any sort of family or social activities. Her role in the family is also very insignificant. "... the only earning member of the family was her brother. He now lies in bed being a disabled. When he does not have any value in the family anymore, how could an intellectually disabled girl like Ayesha have any say?" sister-in-law say of Ayesha raised this vital question.

In a few years time Ayesha will be of marriageable age. She dreams that one day she will get married and have a family. But her family is not so positive. It is already very difficult for a

woman of a poverty-stricken family to get married; this difficulty intensifies immensely for a woman with disability. They say, "... just imagine how much we would have to pay in dowry, do you think we have that amount of money?"

Ayesha's parents often sink into deep worries and anxieties thinking about the future of their children with disabilities, especially of Ayesha. "...Other family members, the community, the society as a whole are reluctant and non-caring to the problems of the girls like Ayesha. Besides, there is no state run institution to care for people like Ayesha. Who will look after her after our death? Can you tell us the answer?" – quipped the sister-in-law of Ayesha. A vital question in deed but yet not answered.

### **Case study - 04**

#### **Anamika: Fighting back in a positive environment**

**Anamika, 12, studies in Class VI. Her father is a traditional herbal healer of Patuakhali district. Anamika is the eldest of three sisters. She had high fever while she was only one year old. As a result of the high fever, her legs bent inwards at a later stage. She was taken to the hospital in Barisal, only to be diagnosed as being affected by polio. The orthopedic doctors advised that surgery may perhaps, be of some help, but as it was not certain, her father was reluctant and opted not to do the operation. Unfortunately, the negligence and ignorance on the part of the father denied Anamika from receiving any further or advanced treatment, eventually leading to permanent physical damage.**

*...Anamika is a complete person in almost all regards but a small error of not being administered the polio vaccination has caused incapacitation that cannot be corrected or reversed. She might acquire education, earn livelihood*

**Anamika walks by herself to school everyday. However, there is little oddness in her walking as she always bends to one side. But what is encouraging is that she is well accepted in her family. This has helped Anamika to accept her disability. As her family have taken the disability normally the neighbours and the community did not also show negative attitude rather they have accepted it as usual. Anamika has very good relationship with her fellow students and teachers of her school. Everyone is very cooperative and helpful to Anamika. She had never been ridiculed for being disabled. Such positive environment has led Anamika to be a confident person in life.**

**But in her daily routine activities Anamika has to struggle with her disability. She is also not able to participate in many of the activities of the home. Anamika does not use any assistive device; this has limited her mobility and made her dependent on others to some extent. – This problem related to her movement really deepens during the rainy season.**

**Even though Anamika is quite confident and independent; she too at times becomes very depressed. At times she feels helpless, especially when she thinks of her future as to who will look after her or if anyone will ever marry her. Anamika is a complete person in almost all regards but a small error of not being administered the polio vaccination has caused incapacitation that cannot be corrected or reversed. She**

might acquire education, earn livelihood on her own, but her disability could never be removed.

Her close ones perhaps accepts her but not all members of the society will accept her. But she refuses to be overwhelmed by her negative thoughts; she knows and has taken the vow to progress towards a better future. She is determined to continue and complete her education, get a job and become self-dependent.

## Case study - 05

### Rozina: A victim of negative mind-set of her own people

Rozina's father was killed by the brute Pak-Army during the Liberation War in 1971. Her mother died soon after. Since then she had been living with her maternal aunty. Rozina's uncle runs a small roadside grocery shop. The family was severely poverty stricken and often had to pass nights unfed. Rozina wanted to contribute to the family. She started to take training in sewing and earn by tailoring. Whatever she earned, she used to give that to the family. But it was still not enough. She then decided to join the Ansars and VDP forces. Besides, at twenty-six she has, perhaps; already crossed the average marriage age. But no body was interested as she had no parents and was not able to pay the dowry. The people whom she approached to arrange her joining the Ansars and VDP forces had ill motives. They had the plan to exploit her sexually in exchange of offering the job. She did not agree and hence was denied the employment scope.

During this period of uncertainty, she came across a woman who had provided her with a job in Dhaka. Due to her good performance she was paid handsomely. After a few months Rozina came back to visit her aunt and the other family members. They were all happy to receive Rozina. But their happiness soon disappeared as misfortune again struck heavily on Rozina. She fell down from the tin roof of the house and lost her senses. When she regained her consciousness, she could not fold her legs and felt a kind of senselessness in her legs. The neighbours wanted to take her to the hospital, but the Imam of the local mosque said it would be of no good as the ill-spirits had pulled her down from the roof. But right after one day Rozina's condition deteriorated severely and her urine and bowel movements were stopped. Seeing no alternative the uncle of Rozina took her to the hospital. She stayed there for more than two months. Rozina improved very slightly but unfortunately had no control over her urine and bowel. Disheartened with the progress she was making Rozina's uncle took her back to their residence in the village. Rozina was placed in the verandah of the house and was given only a jute mat as she had no control over her urine and bowel discharges.

*...It was very difficult for Rozina's aged aunty to take proper care of her. She could not keep Rozina appropriately cleaned. Endured neglect and improper care made Rozina very unclean and detastable. The neighbours started to*

It was very difficult for Rozina's aged aunty to take proper care of her. She could not keep Rozina appropriately cleaned. Endured neglect and improper care made Rozina very unclean and detastable. The neighbours started to pass negative remarks and blame Rozina for her pettiabale condition. Rozina was very saddened at the situation. She felt isolated and alienated. She even started blame herself for her pettiabale condition.

One day Rozina's uncle met a journalist at his shop. He told the journalist about the ill luck of Rozina. The journalist saw the pittingness of Rozina himself and came to know the details talking to her personality. On return to his office the journalist told his colleagues about the sad saga of ill-fated Rozina. One of the lady journalists was extremely moved by the sad story of Rozina. She started to visit Rozina regularly and help her aunty to take care of her. As a result of the care and companionship of the lady journalist the psychological condition of Rozina improved immensely, but the main problem related to her physical disability was deteriorating further in slower phase.

The local journalists discussed about the situation of Rozina and decided to send her to the Center for the Rehabilitation of the Paralyzed (CRP) at Savar. Soon all the arrangements were made and Rozina was admitted at CRP. She stayed there for three months. During her stay at CRP she received a lot of therapeutic treatment/services. She was also able to boost up her-self psychologically by observing the other cases and interacting with them at the center. She saw and realized that there is many more like her and some are in even more severe condition than her. If they can lead a nice life, why not she? She returned home in a wheelchair.

One of the therapeutic workers on a local NGO used to know Rozina. She started to visit her regularly and provide her therapy once a week. The journalists and the local organization took steps to rehabilitate Rozina financially. She was provided with a sewing machine. Rozina also received a loan without interest for poultry farming. She also built a small room of her own. Rozina now earns her own livelihood. She is now independent as a successful earner. She can do all her daily living activities. Rozina even participates in different meetings and seminars.

The journalist was also trained by CRP so that he can administer the therapeutic treatment to Rozina. The journalist used to visit Rozina almost everyday to give the therapy. But the neighbours and other community members did not accept or take this lightly. They started to pass many ill remarks and even accused of illicit relationship. Some also said that the journalist has, perhaps; married Rozina.

The life of Rozina is a tale of sorrow and sadness. In her childhood she lost her parents. She grew up in hardship and just when she was building up a life of her own misfortune struck her again in the form of disability. Now when she has once again started to slowly overcome her disability related odds the society is pulling her down with negative attitude and false accusations. Instead of extending hands of support and cooperation they have resorted to non-cooperation. Rozina wants to live in peace and appeals for positive attitude from the community. She believes that in order to effect any improvement to the pettifol situation of the people with disabilities the negative mind-set of the people must be changed first.

## **Case study - 06**

### **Maltreatment that cost heavily on Sangeeta**

Mussamat Sangeeta Akhter, 18, is a student of Class X. She lives in the village of Raninagar under the Boalia Thana of Rajshahi district. Sangeeta has had very high fever for 10 to 12 days after her birth. The family took immediate action for her medical treatment also. She was first taken to a local doctor who prescribed her very strong antibiotics in inappropriate doses to her age. It was too powerful for her age. The condition of Sangeeta worsened. Her



body temperature dropped down to a very low level and remained so for about eight months after her birth.

Her physical growth/development was very slow up to the age of six year. But the family simply relied on the locally available medical advice regarding Sangeeta's development related problems and did not seek experts' consultations. Her progress in learning to sit, move, walk and talk was extremely slow paced. She learned to walk putting extra pressure on her feet. Such difference in respect of normal growth in comparison to other children made her family worried. They decided to seek further treatment. At the age of seven an operation was conducted on her legs. But despite the operation her right leg became more curved than before. The parents opted for further advanced treatment. As the financial condition of her father is quite solvent, they decided to take her to Madras, India. But nothing mentionable was achieved in Madras. Till date the parents of Sangeeta had spent a huge

***...Sangeeta is very proud of her family support. She is very confident that she will be able to progress in her life and complete her studies if she continues to receive such sincere and wholehearted cooperation and support from her family members. But she is at the same time angered and frustrated at the***

amount of money for her treatment. But to them, all their treatment efforts at huge costs ended in vain. Now, they blame themselves for the condition of Sangeeta. "... it is because of our ignorance and delay in taking appropriate actions. We are to be blamed. We were wrong. We are the cause of ruining our daughter's life"; said the father. At times they also blame the local doctor for the wrong treatment. "... where else could we have gone for treatment? We have to go to the local doctor first. We go there in good trust and if the one who is to save us become the one who devours us, who else could we trust?" exclaimed Sangeeta's father.

Sangeeta is growing up with her disability. Her parents are taking efforts in regard to her rehabilitation. They have tried to give her assistive devices, but she has refrained from using those. She puts two logics for her decision. First, 'the paths (roads) are not adapted or suitable for using the assistive device as such I will require help from others in my movement. Secondly, I prefer to use my own feet in walking just like the others', argued Sangeeta. This stubbornness limits her movement capacity and makes it very problematic and difficult for her. This limitation is also depriving her from being a part of the society. She has limited scopes and opportunities to socialize with others and on the contrary no one would like to mix with her either. She is leading a life without friends, a life in solitary, alienated from the rest around her. However, she has a lot of support from within the family. She identifies this as the prime reason why she is still able to continue her education fighting against the animosities of a harsh world. She at times feels responsible for the suffering of her family.

Sangeeta is very proud of her family support. She is very confident that she will be able to progress in her life and complete her studies if she continues to receive such sincere and wholehearted cooperation and support from her family members. But she is at the same time angered and frustrated at the disability-non-friendly environment around her, especially at the school. "... everyone can enter the school and classrooms with out any problems but they never think of students like us, I will never be able to enter with my assistive device. Why are there no accessibility features in the school?" Sangeeta put it straightwa.

Sangeeta often deeply thoughts about the future. She dreams of getting married, have a beautiful family with two children. She does not want to be dependent solely on her husband. Besides acquiring formal education, Sangeeta also wants to have some vocational training. She would like to utilize these acquired skills to ensure an income even staying at home.

She firmly believes that it is imperative to have both education and vocational skills to be financially rehabilitated in the society. She firmly believes one day her dreams will certainly come true and she will live happily with her small family. Besides these happy thoughts there are issues that still give her lots of pain. “... it fills me with great sorrow when I think of the sufferings of so many others like me, others who still suffer due to lack of accessibility. My pain, frustration and anguish will only be relieved when all the schools and colleges will be built with accessibility features, not forcing us to remember each day in the morning that we are physically disabled”– wished a resolute Sangeeta.

### **Case study - 07**

#### **The unbearing life of Nasima in confinement**

Mossamet Nasima Khatun, 15, is daughter of Nasimuddin. They live in a small village named Shiladahabari in the district of Bogra. The financial condition of Nasimuddin is far below average. Nasima’s mother has to do all the household tasks alone.

Nasima was born prematured. She was born under-weight due to excessive manual labour done by the mother and also lack of nutritious and vitamin enriched food during her mother’s pregnancy. Many thought that Nasima would not survive. But her parents did not give up hopes and tried with all their means and efforts to keep her alive in the early post-natal days.

***...Many people pass by Nasima. But most of them just overlook her as if she does not exist. She becomes very happy while any of her neighbours stop by her. But at the very next moment she is filled with sorrow and sadness...***

God willing, Nasima survived and was also growing up but at a slower pace. When everything was on a positive progress, disaster struck her again. Nasima suffered from typhoid. She had high and uncontrollable fever. Her parents rushed her to a local village doctor. The doctor without any delay gave her a high power injection, perhaps antibiotic; to subside the fever. But no one could realize then how fatal the side effects of the injection would be on Nasima at later age. Nasima recovered from typhoid but a lot of damage was already done to her naïve body. Her parents failed to realize or assess the extent of damage initially. However, soon they realized that their beloved daughter was not able to sit and stand up or not developing as others of her age group. They now knew that Nasima had become physically disabled.

Even today Nasima cannot stand on her own, she cannot hold or grasp anything. She continuously drools and has no control over her body. A field worker of a NGO had identified Nasima and started to provide regular therapy. But no significant improvements were recorded. It is fact that she has immense physical problems but fortunately there has been no damage caused to her intellectual capability. She understands everything. She has great feelings for her parents. Nasima often tries to express her intense desire for a new life, a life without pangs and pains through the tearful expressions of her eyes.

A bamboo platform has been constructed in the verandah of their house for Nasima. She sits in this platform from dawn to dusk. Many people pass by Nasima. But most of them just overlook her as if she does not exist. She becomes very happy while any of her neighbours stops by her. But at the very next moment she is filled with sorrow and sadness, as she is not able to converse or share with her neighbours the feelings that interact in her mind. She

thinks that only if she had active legs, and could walk, then perhaps, she would have also gone to school like other children of her community. But this is a daydream. She is not even able to do all day living activities on her own. But she has always been very eager to study. Her parents also know this. But they also look at things realistically and often ask themselves the pertinent questions, “...her condition is so severe, who will take her to school? How will the others react? Who will help her to study? .... Oh! There are so much problems.” But when Nasima sees her younger sister going to school, her desire and passion for education intensifies. Nasima believes that she can learn and acquire education from her younger sister.

Nasima is now grown up. She has attained much height and weight than before. It is very difficult and labourious for her mother to bring her from inside the house to the platform in the verandah. Nasima does not want her mother to suffer this trouble everyday. She wishes if she could get a wheelchair, that would give her mobility and her mother would not need to carry her everyday to the platform.

For Nasima, life is really deplorable and unbearing one. She hates the life she is now living. She has no charm in living a life in such a cruel situation. Still she dreams of a day to come when she will get solace to her painful experiences by an act of divinity or otherwise.

### **Case study - 08**

Not the person, but the land earned some respectability for Rabeya

**Rabeya's husband is a farmer. They live in a ‘Char’ of Chittagong. They have a nine-member family. Rabeya is mother of one son and three daughters.**

Rabeya has severe physical disability. When she was three years of age, she had typhoid. It affected her legs. Both legs became paralyzed. Her parents spent a lot of money for her treatment but with out any result. In the name of treatment her parents run after unrealistic ‘magical cure’ but they never sought for the therapeutic cure or rehabilitation support for Rabeya, which could have really changed her situation.

*...It is though unfortunate but true that she has no role in the decision making process of the family. Her opinions have very little or no value. Rabeya feels that whatever respect or consideration she receives as a member*

From the very childhood Rabeya had to encounter many odds and barriers. No one of her age would like to interact to or play with her. The community people treated her as a bad omen and also as a symbol of ill luck. Rabeya used to be ridiculed, called by disability, not by names; and detastefully treated. She was not even allowed to meet with persons who would visit their home. She had to live like a prisoner even in her own home. She had no scope or opportunity for schooling. In fact, she had to no opportunities like others non-disabled children. She lived a life of seclusion, neglect and discrimination. It was full of sorrow and sadness. No one even tried to understand that a physically handicapped person might have other talents or capability– intellectual or other potentials too.

As Rabeya's father was rich it was possible to arrange a marriage for Rabeya at the cost of high dowry. She now lives in her husband's house along with her children.

Rabeya faces a lot of difficulty in her movement, especially in the rainy days. She normally sits in her room during the rains. Besides, there is not much accessibility provision for her movement in and around the home. She is also not able to join the different social gatherings. Even if she joins she has to endure the negative attitudes shown to her. These very attitudes and mannerism pains her and in a sense forces her to stay inside the doors of her house. She also feels depressed, as she has to, for most of the times depend on others.

There is hardly any recognition to the works that Rabeya does. She tries her utmost to do most of the works, but her disability often acts as a barrier. She has some problems in working in standing position but she can do all the domestic jobs sitting down. However, she is a successful mother. Rabeya has been very successful in rearing up her four children. Disability might have defeated Rabeya in many a ways but she has won over when it is the question of motherhood.

Rabeya blames no one for her disability. She considers it as her fate. Her children love and respect her very much. She too loves and cares for them to the best of her capacity. It is though unfortunate but true that she has no role in the decision making process of the family. Her opinions have very little or no value. Rabeya feels that whatever respect or consideration she receives as a member of the family is because of the property she has received from her father. She feels embarrassed at the fact that whatever little recognition or respectability she has earned is for the land she possesses. Rabeya wants a change in the situations for a better environment for people with disabilities.

### ***Case study - 09***

Shila is firm in her belief— Life does not end in disability

Shila is the third child in a family of three sisters and one brother. She was born in a rich family in Jhenaidah. Shila has cerebral palsy related physical problems. Her mother fell down from the roof of their house at the sixth month of her pregnancy. As a result she had long labour pain. It lasted for more than a day. Within a few days of her birth, Shila's parents noticed some abnormalities in her. She did not make movement like other non-disabled babies. Shila could not move her left arm and leg. The parents became very concerned and sought treatment from the local herbal and traditional healers. Shila's parents become disappointed and frustrated noticing no improvement of the physical condition of Shila and eventually they stopped treatment that could cure Shila.

Shila's father owns a few transport vehicles. He also has some shops in the main market of the town. Shila was enrolled in to a school, just like her other brothers and sisters. But this agreement for Shila's education met a premature end. She could continue studies only up to Class III and then discontinued in the face of negative attitude prevailing both in her family and at the school. Shila now stays aloof and seemed alienated at home all the times. Seldom her cousins play with her. She is overtly neglected and often discriminated by the family. She is never given new

clothes like her other brothers and sisters. The used clothes of her elder sisters are normally passed on to her. Shila likes to go outside her home, but no one is willing to take her out. Besides, whenever she goes out the neighbours crudely misbehave, rebuke and call her by disability in a most inhumane way.

Shila faces severe difficulty in using the roads, especially when it is uneven. As she is unable to move her left hand and leg hence she has to depend on others in her activities of daily living (ADL). The home, especially the toilet has no accessible features suitable to her. She is even unable to use the toilet nearest to her room. She has to step down the stairs to use the toilet on the ground floor. None in the family now seemed to be attentive to her needs and the odds she encounters. They are either ignorant or indifferent to her difficulties and problems. She now considers herself as a burden to the family.

*...despite her dreams and determination the family thinks that Shila can achieve nothing. It would be wastage of energy and resources if she were given the scope to pursue education and undertake skill development training. Shila*

is deeply disheartened and disappointed when she hears such words of Shila spends most of her time in the grilled verandah on the second floor of their building. She leads a caged life. Whenever she feels sad or disheartened, she stands by the grill and cries quietly. From the verandah, which is on the roadside, Shila over sees other girls – of her age – going to schools. The very scene reminds Shila of her incapacitation and makes her despaired. “If I were not disabled, I could also go with them to school,” exclaimed Shila. She understands others of her age have learned a lot from the school, which she does not know. But she firmly believes that if she had the chances/options open then she would also have learned a lot. She still hopes and dreams too that this opportunity might once again be offered to her. Shila also hopes of acquiring computer skills. She also wants to be a draftsman. She wants to be financially self-dependent through pursuing education and developing vocational skills.

But despite her dreams and determination the family thinks that Shila can achieve nothing. It would be wastage of energy and resources if she were given the scope to pursue education and undertake skill development training. Shila is deeply disheartened and disappointed when she hears such words of discouragements from her parents and family members. Adversities could not stop Shila from dreaming – dreaming of better days when she will be able to prove it wrong to others that she might have disadvantages for being disabled but it is not the end of life.

## Case study - 10

Neli\* does not know what is her fault

Sadia Jesmin Neli, 16, is a girl with intellectual disability. She was born in a middle class family in the district of Noakhali. Neli had very normal growth at par with her peer group. But her parents were very ignorant and careless. They did not give her prescribed immunization — vaccinations and injections doses that are given to the newborn infants in phases. Neli at the age of three plus had once severe seizures. The parents immediately took her first to the traditional healers and then to a doctor. She was given medicines to control the seizures. It worked well but made Neli drug dependent. Now, she has to take medicine everyday. If she is not under medication, she suffers from seizures.

Neli's parents could notice her intellectual disability when she grew up and started showing

*...They used to allure her to come outside the home and taking the advantage they used to abuse her sexually. One day her father could detect the fact. He got shocked and angered. He tried to refrain Neli from such involvement through persuasions and even by physically assault. But Neli was ignorant of the situation and could not understand her faults. Her parents also wanted to*

behavioural abnormalities. Her words and sentences were usually abnormal and very inappropriate to particular situation. Almost everyday after sunset, she used to go out of home, may be unknowingly; and sit silently inside the bushes near her home. The family member had to seek her out and even apply force to bring her back.

Where Neli grew up physically as young woman she became an object of lusture of the local wayward boys. They used to allure her to come outside the home and taking the advantage they used to abuse her sexually. One day her father could detect the fact. He got shocked and angered. He tried to refrain Neli from such involvement through persuasions and even by physically assault. But Neli was ignorant of the situation and could not understand her faults. Her parents also wanted to take action against the delinquent boys but were also fearful that it might bring more dishonour or even danger to Neli and the family. They finally decided to keep it a guarded secret and not to take any action.

**A female social worker of a local NGO could know about Neli and her situation from the community sources. She felt disgraced for the unkind society. She could not comprehend how could the boys exploit Neli, a girl who was intellectually disabled; who could not differentiate the right from the wrong. She visited Neli's home and discussed the matter with her parents. She explained that beating Neli would not solve the problem. Being an intellectual disabled Neli has limitation in understanding facts and their consequences too. She requires a different approach of discussion. The social worker gave a lot of time trying to explain the situation and also the possible dangers that Neli could face because of her pro-active interactions with the delinquent boys. The parents had always thought that Neli could never be educated. But the social worker had explained that it is possible for persons like Neli to be enrolled into schools and be educated. The social worker with the support of a local development organization was able to enroll Neli into an inclusive education center. Neli is also learning sewing skills in that organization. The social worker also trained up Neli on the activities of daily living and on doing household works. Currently, Neli**

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\* Actual name has been concealed due to personal request

is able to perform some of the domestic tasks. Neli is now leading a much better life. She also dreams like most girls of getting married and having a family. As her family is well to do it might perhaps be possible for them to arrange a marriage for Neli. But Neli is worried whether her husband would be able to understand her. Would he (the would be husband) accept the limitations she has due to her intellectual disability? — absorb Neli's thoughts most of the time.

### **Case study - 11**

#### **Mini\*: The Unwanted Member of the Family**

Mini, 20, lives with her parents in Noakhali. Mini is second in a family of three sisters and one brother. Her father is a college teacher. Mini has multiple disabilities viz. cerebral palsy and intellectual disability. Mini's mother married her first cousin when she was only fourteen. Mini was born only a year after the marriage of her parents. But the birth was full of complexities. She was a premature baby with severe under-weight (only four pounds). She also took an unusually long time in crying after her birth. Her mother also did not have enough breast milk to feed Mini. Mini started to grow under such difficult situation. Due to malnutrition and physical weakness she used to fall easy victim of various diseases. At the age of ten months Mini had pneumonia. She also suffered from typhoid when she was only one and an half year old. After a few day of uncontrolled fever Mini's parents took her to a local doctor. But it was already too late. The doctor examined Mini and opined that due to typhoid a lot of damage has in the meantime been caused to her brain.

As time passed, Mini's mother observed that she was not developing or growing like others

*...Mini is also developing physically as any other girl. This has also turned out to be a source of worry for her mother. She gives Mini very little food to stop her growing physically. They are under the impression that if she grows*

of her peer fellows. She expressed her concerns to her mother-in-law, but she was told that it is normal as most of the family members were also slow in early development. The mother was relieved and paid no further importance or attention to Mini's slow development rate.

**Years passed out but no mentionable improvement was observed in the development and growth process of Mini. The problems associated with her growth only increased and turned into complexities as time rolled on. The neighbours started to blame the mother of Mini for her condition. This hurt and grieved Mini's mother. Mini's mother, very much in shock and despair, took and left Mini to her maternal grandmother in Chittagong. This shifting acted as a blessing in disguise for Mini.**

The grandmother took Mini to Chittagong Hospital for treatment and therapeutic services. Mini was prescribed some therapeutic exercises to be practiced regularly. With a strong will force, Mini practiced those therapeutic exercises, though tough; regularly which yielded positive results and Mini started to walk on her own. She was then nine years old. Hoping further improvements Mini's mother brought her to a Dhaka-based organization working on Intellectual Disability for further advanced support and care. The doctor of the organization informed that Mini has cerebral palsy and also intellectual disability. The mother was also

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\* Actual name has been concealed due to personal request

advised to bring her regularly to the center. Unfortunately, it was not possible as they lived far away from Dhaka and also unable to afford the huge cost, Mini's mother lost hope and returned back to their home.

On return to home Mini's mother was deeply dissatisfied as nothing much was possible for Mini. She resorted to a local spiritual healer. But it yielded no positive result; on the contrary wrong treatment caused further deterioration. Her mother also went to many persons hoping a magical cure. But all these were useless. Mini's mother found herself in a situation of helplessness, confused and uncertain as to the next course to follow. She was so disappointed and also started to blame Mini for all her and the family's misfortunes.

Mini now spends her days encountering a lot of neglect, maltreatments and rebukes from her parents. As she has not received any form of training, she is unable to perform most of her daily living activities. She cannot use the toilet or bath alone. Mini realizes that she is being maltreated or scorned. This makes her anitiated, angered and stubborn. She expresses her negative feeling by staying in a corner of her room. When guests arrive in their homes she too wants to interact with them, but she is not allowed. Besides, no one wants to give her time too.

Mini is also developing physically as any other girl. This has also turned out to be a source of worry for her mother. She gives Mini very little food to stop her feel other usual physical desires and demands too. Perhaps, there may be none physical growth. They are under the impression that if she grows up Mini will naturally willing to marry her and as she is intellectually disabled, she might unknowingly resort to socially unaccepted means to meet her physical desires. But the present practice of giving Mini limited food is having severe effect on her health. She is extremely malnourished and has become an easy prey to diseases.

Mini's father is utterly frustrated at the situation of his daughter. He hardly takes any care of his children. He spends most of his time away from his home just because he has a disabled daughter. The family, especially her mother is desperately trying to keep Mini in any rehabilitation center for the disabled. Such placement of Mini would help them to get the other daughters married. Mini is simply taken as a burden to the family, a burden that they would like to deport. Mini is now an unwanted member of her family leading a painful and harsh life full of sorrow and sadness.

## ***Case study - 12***

### **Sumi ponders over the unanswered questions**

Sumi, 10, has cerebral palsy. When she was three months old Sumi had high fever. One day it was observed that Sumi become still and making no movement. She was also not breathing. It was presumed that Sumi was dead. All preparation were completed to bury her. But suddenly she started to move shocking everyone. Immediately she was taken to a village doctors and subsequently to religious healers. They offered treatment in their respective manner. But the condition of Sumi deteriorated with the passage of time. Lack of proper care and maltreatment made her very weak. As Sumi gradually developed her mother observed that she was not able to do the activities that any other child of her age group would normally do. Her mother continued to seek treatment for Sumi in her limited capacity. But no such attempt resulted to any positive changes in the condition of Sumi. Her mother gradually got disheartened and lost interest in Sumi, specifically in her treatment. As a result the condition of Sumi only worsened.



The father of Sumi soon deserted her and her (Sumi's) mother. Sumi's mother was left alone to take care of Sumi. They had then to move to her maternal grandparent's home. Now Sumi spends most of the time lying in the open space in front of their home. She stays there like a lifeless being. Sumi's mother tries her best to earn money and contribute to the income of her father.

*...There is no one in the family who can give her all the care she needs. Her mother cannot solely be blamed for not taking care of Sumi. She had tried before but has to surrender to the harsh conditions and cruel realities of this*

Sumi has no acceptance to the neighbours. She is often ridiculed, called by the disabilities and labeled as a symbol of sins committed by her family. No one tries to communicate or interact with her. She is even physically beaten at times by the family members for doing such things which were beyond her control. Sumi is hurt and saddened by the maltreatments of her family members. Often she cries in silence. Amongst the family members, only her grandmother is slightly different. She is kind and caring to her. But she too is aged and it is not always possible for her to take adequate care of Sumi.

Currently at the age of ten Sumi is still not able to eat, hold anything, sit or stand by herself. Her muscles stiffen whenever touched. She has no control over the muscles of her hands and legs. Sumi always needs assistance for toileting. Caring for her takes a lot of time and energy. There is no one in the family who can give her all the care she needs. Her mother cannot solely be blamed for not taking care of Sumi. She had tried before but has to surrender to the harsh conditions and cruel realities of this world. She no longer has the mental or physical strength to look after Sumi. She is a human seemingly lost in her fight against poverty and the disability of her daughter.

Despite all these realities, one cannot help but wonder if Sumi were provided with the right kind of treatment and therapeutic services things would have been otherwise. Had it been so, Sumi could lead a near-normal life.

Who are to be responsible for Sumi? Is it not the responsibility of some one to care for her? Would she ever receive the much needed therapeutic services? Do child rights, human rights, civil rights have any meaning to or role for Sumi? Would she only live a life in neglect and pain? Sumi often stares at the vast bright blue sky, contemplating on such and many more questions that rage inside her small soul.

### **Case study - 13**

Usha: The brute victim of dowry

**Usha Rani Devi was born in 1955 in the district of Chittagong. She was growing up as usual and enjoying life like other children. At the age of two, Usha had chicken pox. The severity of her illness was so intense that she lost her eye-sight. She was deprived forever of the most value sensory power of vision to the world around.**

**Her parents were devastated at the condition of their beloved daughter. They tapped all possible sources of treatment including allopathic, herbal, traditional, homeopathic and religious healing and even black magic. But nothing did work. Finally, the parents realised that their beloved daughter has lost her vision forever.**

To Usha the beauty of dawn, darkness of night, deep blue skies, green pastures and the scenic beauty of the world — all become matter of no value.

*...When Usha was of three or four years her parents tried to educate her in the home. She now tries to assist her niece and nephews in the primary*

Usha is the third among her three sisters and four brothers. When she was 27 years old, her father arranged a marriage for Usha. Her father was a simple and honest man who thought that if Usha were married some of her pains and sufferings might be reduced. He also planned to give a small plot of land with a house to his son-in-law just beside his own so that he (the father) could be able to see the daughter unto his death. Unfortunately, Usha's husband was a very dishonest and greedy man for dowry. After six months of their marriage the son-in-law deserted Usha and decamped finally. Usha's father was deeply shocked and saddened at this inhumane incidence sensing the pains and suffering that his daughter was enduring. It was too much for him to tolerate, he fell ill and tragically died.

Usha now stays at her father's residence. She is fond of social get-togethers and events, but she is unable to attend due to the limitations of her eyesight. Besides, her brothers and sisters are unwilling to take her along with them. The family members usually leave her behind look after the house in their absence. When Usha was of three or four years her parents tried to educate her in the home. She now tries to assist her niece and nephews in the primary education.

Usha has deep rooted rage against the society. She no longer wants to seek assistance from anyone. She has accepted the neglect and disrespect that is shown to her as hard reality of life. Despite all the darkness around her she is still able to see light when she recalls the pleasant memories of her father.

Usha loves children and the children also love her. Usha hopes and dreams that she will be able to spend her life by loving and being loved by the children. Children seem to become the only one who can understand Usha and be her true companion.

### **Case study - 14**

Chabia fears the dark world most

*"If I were not a disabled, I would have also studied and could get a job like you"*, said Chabia in tearing eyes. Chabia lives in Faridpur. She is one of the six children of Karim Munshi. Destiny has been very cruel to the Munshi's. All the six kids are disabled.

Chabia was very normal after her birth and apparently was leading a usual life. But the parents could not realise that her disability was congenital as the symptoms were initially unexposed. With the passage of time she started to have low vision and could not see at night. Chabia was taken to the local doctor. On examining Chabia, the doctor prescribed medicine. But it did not work and soon Cabina became blind.

Chabia is now twenty-six years old. There are eight members in her family. Her sister Kohinoor has visual impairment, brother Kashem has multiple disabilities, sister Razia has low vision, brother Kawser is physically and visually impaired, brother Kader has also visual

impairment. Among them only Kohinoor is married. She had been married to one of her cousins. The couple also lives with their parents.

***...Eight years earlier Chabia was married to a man of her village. She loved her husband very much and was very happy with the relationship. But her happiness did not last for long. After a few months of their marriage the man disappeared deserting Chabia in one fine day. She was disheartened. Even***

Chabia had a childhood filled with sufferings, neglect, ridicules, discrimination, and etc. As all the brothers and sisters are disabled none was able to help each other. It was virtually impossible for their parents to take equal care of all the children. Chabia does not want and also feel uncomfortable to mix with people, as she always felt inferior to others. She along with her sisters and brothers prefer to stay in isolation and inside the doors.

The community people had never accepted them. These unlucky kids have always been a source of negative discussion and criticism of the society. They were called by bad names, ridiculed and unjustly rebuked. Some of the community people even believed that they were suffering because Allah has punished their parents for some unforgivable sins that they had committed.

In 1992, a worker of a local development organization, working on disability issues, selected Chabia as a member of their beneficiary group. She was imparted mobility and other trainings and was also given a white cane to facilitate her movement. Chabia has also received credit from the same organization for poultry farming. The training that she had received has enabled her to contribute to her household activities. But Chabia still feels guilty for not studying and remaining unlettered.

Eight years earlier Chabia was married to a man of her village. She loved her husband very much and was very happy with the relationship. But her happiness did not last for long. After a few months of their marriage the man disappeared deserting Chabia in one fine day. She was disheartened. Even then Chabia still waits for the man hoping he would return one day.

She however knows that even though she loved the man like a demigod, her husband had deserted her only because of the fact that she is a disabled one. If they had a child, Chabia feels, she could have spent her life with that child. Chabia spent most of her times alone in seclusion. Even though other members of the family try to get her engaged in family involvements and social visits, but she refrains from such involvements in most of the cases.

Even though all of their children are disabled, the parents of Chabia have always loved them in tender care. They tried sincerely to raise them equally without neglect and discrimination. Their financial condition and property had always been a big strength and a source of courage and determination to face all obstacles and live a happy life with their children with disabilities. The courage and mental strength of Chabia's parents are praise worthy. Their patience and dedication are imitable by others in the society. Despite begetting six disabled children they have not totally despaired. Chabia and all of her brothers and sisters are lucky that born in this family. The family respects Chabia. Her opinion is valued with importance in all decisions of the family.

Despite the supports from the family, Chabia often sinks into deep depression. After facing this harsh realities of the unkind world she at times no longer desires to have her vision back, she states that the darkness of this world is much worse or bitter than the darkness resulting from loss of vision.



## Case study - 15

### Koli wants to set example for others

The child was born normal like others and could see the beauty of the nature as usual but cannot do it now in her own eyes because she has lost the vision. It happened due to the carelessness and ignorance of her parents. Sixteen-year-old Zakia Sultana Koli is the youngest among five brothers and sisters. Her father had passed away. She is now under the guardianship of her eldest brother. However, Koli is now studying in class seven at Baptist Sangha School for Blind Girls.

Koli was born as a healthy child with perfect eye-sight. At the age of two, Koli had diarrhoea. Koli's mother was not at home during that time. Her grandmother then nursed her. But due to ignorance the grand mother could not properly take care of her. As a result Koli suffered from severe dehydration. This dehydration virtually affected her eyes. Latter Koli was taken to the doctor by her uncle who advised that an operation at the age of twelve would permanently solve Koli's problems. But her father was impatient and had done the operation only at the age of seven. After the operation Koli repeatedly scrubbed her eyes which resulted in blood discharge causing further damage to her cornea. Koli ultimately become visually impaired as a result of ignorance of her parents and perhaps also improper medical services and care.

In 1992, a cousin of Koli enrolled her at Baptist Sangha School for Blind Girls. But the

***...The boys of the school ridiculed and teased her. She became sad at the lack of awareness and limited knowledge of the fellow students who had not been taught to accept others who are different. Besides, Koli felt insecure as she***

parents were reluctant in sending Koli to the school that is far off from their home. They were worrying for her safety. Her parents wanted to enroll her in a general school near to their home. However, the eldest brother of Koli was finally able to convince and persuade their parents to let Koli to travel to Dhaka and study at the school.

In 1996, Koli moved to Bibekanondo High School. The boys of the school ridiculed and teased her. She became sad at the lack of awareness and limited knowledge of the fellow students who had not been taught to accept others who are different. Besides, Koli felt insecure as she was treated like an alien in the school. As a result, she again returned to Baptist Sangha School for Blind Girls.

Koli had always been interested in music. As a matter of fact Koli showed keen interest in cultural activities. Her elder brother always inspired Koli in learning music. Koli even had received first prize in music competition at Shishu Academy. She has also been rewarded for her performances in poetry recitation and performing in drama. After completing her schooling, Koli wishes to study in music. Her elder brother bears the costs related to her education and music lessons. The brother also hopes that one day his sister will become a renowned singer. All the people of her neighbourhood, relatives and friends encourage and inspire Koli in her pursuit of education.

Koli does never think of marriage in specific. But she has the common desire of having a family, just like other girls of her age. However, she wonders if this will ever happen, as she is disabled. But she would first of all like to work for the society and make it a better place to live in honour and dignity, particularly for the vulnerable ones. She likes to interact with and inspire those who are in a much vulnerable condition than her.

Koli feels helpless when she is treated differently by the society. But Koli otherwise considers herself as a happy person. She wants to bloom from a bud to a flower in the world of music, she dreams of setting an example, which can be a source of inspiration and motivation too for many others like her in the future.

## **Case study - 16**

### **A caring husband gave Rawshan a new life**

Rawshan, 25, lives in the village of Charfession of Bhola district. She is the only daughter in a family of four children. Rawshan was born as a visually impaired. In the early days, she had limited vision but it deteriorated quickly. Her parents failed to realize the severity of her visual problems until she was one year old. She was not responding as other children do at that age. Only then the parents could understand that their daughter was severely visually impaired.

**Rawshan was not able to perform the activities of daily living. She had a lot of mobility problems. At this stage of her life a social worker of a local NGO came to know about her. The social worker started to train her on mobility and on the activities of daily living. She learned quickly and soon was able to do things on her own things.**

*...As Rawshan grew up, she fell in love with a day labourer. The affair ended into marriage. Ibrahim was fascinated at the confidence and desires of Rawshan to be successful in life. Her disability was not a barrier to their*

As Rawshan grew up, she fell in love with a day labourer. The affair ended into marriage. Ibrahim was fascinated at the confidence and desires of Rawshan to be successful in life. Her disability was not a barrier to their wedding. After their marriage, her husband, Ibrahim took her to many doctors, but there were no success. They both have now accepted that Rawshan will never get back her eye-sight. Rawshan does all the household works, but with difficulties. However, she is always helped and assisted by her husband. The man is always cooperative to the wife.

Rawshan did not have the opportunity to receive education or obtain training in any income generating skills. She feels safe with her husband, who loves her very much. But at times she reflects upon the future, especially when her husband will not be there to look after or care for her. She is not alone, but she has also a daughter to look after. Rawshan wants to in the future to receive skill training and be engaged in income generating activities to make an earning for herself and the family.

Rawshan had a dream – a dream of having a family that would be her own. She has that dream fulfilled. Rawshan is loved very much by her husband and her daughter. The support and cooperation of her family members and her neighbours encourage and imbibe her to look progressively at life. She values this cooperation much. *“...There might be a lot of difficulty if you have disabilities, but if you have scopes, cooperation and a positive environment you can achieve a lot. I only hope others like me can have the same kind of support and cooperation that I receive,”* said a contented Rawshan.

## Case study - 17

### Samapti: The girl with a vision of the mind, not eyes

Samapti Rai, 17, a severely visually impaired, is the youngest of a nine members family. Her father is a traditional herbal healer. Samapti had typhoid when she was only three years old. The typhoid left severe effect on the eyes of Samapti. She developed cataract. Her parents immediately took her to doctors for treatment. But no improvement was achieved with medicine. However, the doctors advised that if a cornea were implanted she would regain her eyesight. As she was too young such operation was not conducted. Her father did not want to take the risk of surgery even when she had grown up.

*...But getting enrolled into the college was not easy. The college authorities were initially reluctant and hesitant in admitting Samapti. They apprehended that they would have to bear additional problems if they had enrolled Samapti. But Samapti was finally able to convince the authorities arguing,*

Samapti's mother was profoundly moved at the condition of her daughter. She was working at the Department of Social Services. She just resigned from her job to take care of Samapti. When she was only four her mother wanted to enroll her into a local school that had Integrated Schooling scopes for the visually impaired. The school authorities overwhelmed by the interest and pursuance of Samapti's mother enrolled her into class one as because she was only a six-year-old girl. She studied in this school till class four. Samapti was able to learn Braille in this school. During this time Samapti also learned music from a music teacher. Her parents and her sisters were really supportive in Samapti's efforts in learning music.

From this school Samapti was transferred to Barisal Blind School for Girls. She studied there for one year residing at the hostel. But Samapti was not able to adapt to and adjust with the environment of the new school. She left that school to be enrolled into Baptist Sangha School for Blind Girls (BSSBG) in Dhaka. She studied here up to class eight. The scope for education at BSSBG was fine but she did not have the proper opportunity to learn and practice music. As a result she again moved back to Faridpur Integrated School and completed her S.S.C. During her S.S.C examination she had to encounter a lot of barriers, as she did not have her books in Braille. Samapti had to use audio cassette player as an alternative media. Despite various obstacles, Samapti did very well in the examination and was awarded scholarship.

Currently, Samapti is a first year student of Sarda Sundori Mohabiddaloy, Faridpur. She is the only visually impaired student of this college. But getting enrolled into the college was not easy. The college authorities were initially reluctant and hesitant in admitting Samapti. They apprehended that they would have to bear additional problems if they had enrolled Samapti. But Samapti was finally able to convince the authorities arguing, *"Education is my Right, and you can't deprive me of obtaining education just because I am a disabled person"*. Samapti is very serious about her

studies. Her family members and all her fellow students assisted Samapti much in her education.

Samapti always participates in all family events and social activities. Samapti herself and no one in the family consider her to be a disabled person. She is so much loved and cared by all in her family that she never felt negatively about her disability. Samapti is given equal importance in all decisions of the family. Her friends too share with and seek her advice on many of their affairs.

A local organization working for the visually impaired persons had spotted Samapti when she was only four years old. Ever since then this organization assisted Samapti in many ways. Currently, Samapti is engaged as the music teacher of a special school of this organization. She is now also teaching music to many more visually impaired children. Samapti had also received skill development training on producing handicrafts. She is an active member of many cultural clubs and organizations. She is taking lessons from two music teachers. In 1997, Samapti had received first prize in the Rabindra Sangeet competition organized by Khela Ghar in the adolescent age group. In 1999, she became first in the national competition organized by Jatiya Rabindra Sangeet Niketan. She was awarded books, one Tanpura and Five Thousand Taka in cash. Samapti was very happy and proud for the award she received. She gave the award money to her father to construct a room. Samapti had also performed in different programs of the Bangladesh Television (BTV). She even visited different parts of the country to render music in cultural programs. Samapti now dreams that she would one day become a very renowned singer. She is not only versed in singing but she also possess great acting skills. She has also performed in many plays and dramas.

Samapti also has a strong desire to become a Lawyer. There is a special reason behind her intention. One day as a young child, while she was going with her father to take her music lesson, a local Lawyer stopped them and queried where they were going. When the man heard that she was going to music class he laughed and remarked, *“What is the use of teaching this blind girl? Blind girls like her have no value in the society. It is better that no resources is wasted on her.”* Samapti and her father were very hurt at the remark. Ever since then she had promised to herself that one-day she would also become a Lawyer like that unkind man and take revenge for her insult.

Samapti is self-conscious about her situation and the future too. She has not yet decided when she would get married. She believes before getting married she would need to become fully independent. She aims to prove to others that she is not a burden on anyone through her deeds, not words. She has no regret for being a disabled. Samapti has read the biography of Helen Keller. She believes that one does not need eyes to appreciate the beauty of this world, the vision of the mind is adequate.

### **Case study - 18**

#### **Lucky worries for the luck of her son**

Lucky, 18, is the daughter of Md. Sadequr Rahman, a primary school teacher of Jhenaidah district. Lucky was showing abnormalities ever since her childhood. She used to walk in differently and talk in an unorganised manner. She had also difficulty



in maintaining physical balance. As a result she met a lot of accidents. Once she was drowned in a pond while bathing. The neighbours rescued her after a long time. But still no one was really able to identify what was causing such abnormalities to Lucky. She was taken to doctors for treatment but no improvement was marked. Lucky is a case of mild intellectual disability.

*...When Lucky was sixteen she was married off. All the members of her family had thought that her problems would no longer be there once she is married. But after the marriage her problems become more visible especially in the new environment. She often used to withdraw herself, remain isolated*

The parents of Lucky cared for her to the best of their capacity. She was also enrolled to a school. Her father took special care for her education. She was able to study upto class five. As she was not progressing well in her studies the parents decided to get her married. When Lucky was sixteen she was married off. All the members of her family had thought that Lucky's problems would no longer be there once she is married. But after the marriage her problems became more visible especially in the new environment. She often used to withdraw herself, remain isolated and inattentive and talk to herself. Lucky's behaviour started to raise questions in the minds of her in-laws. In the initial days her husband paid no heed to such observations of his family members. He had no dearth of love to care for his wife. He always took special attention to look after her needs and wants. After two years of their marriage, Lucky gave birth to a beautiful little baby. The news brought great happiness to her relatives. They hoped that Lucky's abnormal behaviour would perhaps change now. But in reality she could not discharge the responsibility that she should have done as a mother to the child and as a wife to husband. As such Lucky's acceptance gradually diminished in the family of her husband. All her in-laws started to scorn and ridicule Lucky. In the back-drop of such an unfriendly situation Lucky's husband took her to her father's house and left her there. Her father again sought treatment for her but it did bring no good. As days passed she lost her acceptability gradually.

There is no end to the worries and anxieties of Lucky's parents. She along with her son still live in her father's home. Her son is now five years old. Her husband has married again and lives with his second wife. He no longer maintains any contact, not to speak of a relation; with Lucky. He also shares no responsibility or bears any costs related to the expenses of rearing their son.

With passage of time Lucky's condition has deteriorated severely. She can now perform none of the activities of the family. She cannot even do the activities of daily living rather she has to be dependent on others on all counts. She has lost acceptability in her father's family too. Everyone now consider her to be a symbol of crimes committed by some one else. Lucky is neglected and discriminated. Her neighbours ridicule Lucky and call her by bad names. Most of the time she is kept hidden and locked in a room. However, there are certain rare times when Lucky is able to think logically. During those times, Lucky only worries about the future of her son. Such thoughts lead her to shed tears of pains and sufferings.

**Case study - 19**

**Friendly environment helped Lisa most**

Dil Ara Zaman Lisa, 24, is a smart and active lady. Her father is a retired service holder and her mother is a teacher of a special school. Lisa lives with her parents in Dhaka. They are two sisters. Both of them are speech and hearing impaired. However, the degree of Lisa's hearing loss is much higher than that of her sister.

Her parents were able to identify that she is a case of hearing impairment on her first birthday. They took the best possible efforts to provide treatment to both of their daughters. They tried all available interventions including religious and traditional healings. Though the family was in financial difficulties yet they did everything for a cure to the hearing problem of their daughters. But due to their ignorance and lack of information from the attending doctors they could not realize that the hearing impairment of their daughters was permanent and it can never be cured.

*..The hearing aid was a source of curiosity to all. Some of the students also called her by bad names and often ridiculed her. But with patience, merit and time Lisa has been able to win the hearts of all her classmates and peer students. They no longer mock or behave badly with her.*

One-day Lisa's parents saw an advertisement in the newspaper that a foreign specialist on hearing impairment issues will carry out a camp to assess hearing losses of people with hearing impairment. The parents took her there for assessment her hearing losses. After her assessment the expert advised her to procure a hearing aid. But due to lack of money Lisa's father could not buy the hearing aid.

On persuasion from her mother Lisa was however admitted to a school in Dhanmondi, named HICARE run by a businessman under the advice of the same foreigner. A year after, another foreigner appreciating the interest and commitment of Lisa and her mother gifted Lisa with a body worn hearing aid. This is a memorable day for both Lisa and her mother. Under the guidance of the instructors and the teachers Lisa started to learn the application of the hearing aid and how it can help her to communicate with others.

After studying for three years at HICARE School Lisa enrolled herself into a general school in Dhaka. She had to sit for an admission test like all other to qualify to get admitted into the school. Lisa was very interested in and committed to her education. Her mother laboured very hard to help her daughter in her education. However, the initial days at the school were not very positive. The teachers did not know how to help Lisa in her study in the classes. But as the teachers were very cooperative, they gradually gained experiences as to how they could support Lisa in the classroom in her studies. They also allowed Lisa to answer questions in writing even in the oral examination. Besides, her mother used to go to her school once a week to observe her learning capability and limitations too and also to share with the teachers about Lisa's overall performance. Based on the findings her mother used to take special attention at home. As a result of hard work of her mother and the support of teachers Lisa was able to perform extremely well and secure top position in her examinations.

The peers at the school were not always friendly in the initial days. She was like an alien to them and an object. The hearing aid was a source of curiosity to all. Some of the students also called her by bad names and often ridiculed her. But with patience, merit and time Lisa has been able to win the hearts of all her classmates and peer students. They no longer mock or behave badly with her.

Lisa is skilled in many other areas like in painting, embroidery and boutique. She is also well capable in doing household activities. Through these skills she is also able to earn some money. She spends these according to her own will. Interestingly, Lisa like to buy presents for her parents.

Lisa were interested in studying at the Arts College. But she was sick during the admission test. She is currently studying B.A. Honors at Home Economics College. She likes the subjects she is studying, as there is a lot of scope to be creative. She has a lot of friends in the college who assist her in her studies.

Lisa always dreams of becoming independent in her life. She wants to prove that if opportunities and scopes are offered equally to the hearing impaired persons, they too, like others; would be able to blossom and establish in life with equal status in the society they live in.

## Case study - 20

### Dolly: When the sisters are hostile

Dolly was born with disability. She has multiple disabilities. Even at the age of 35, she acts like a two-year-old baby. Dolly lives with her mother and her six brothers and sisters. Her father was a businessman. He died a few years back.

Dolly is the first child of her parents who had lot of dreams or aspirations with her. In the early months of her birth none could realize that Dolly had problem by birth. However, by the seven months her parents identified that she had problems in her movements and stares. They immediately took her to local doctors for treatment. But the local doctors could not diagnose the problems of Dolly. As such they gave false hope that in course of time Dolly would recover and be cured. But on the contrary, with the passage of time the condition of Dolly worsened and her problems became distinctly evident. She was not able to walk. She could not eat any solid food. Her parents, already afraid, anxious, sad and confused of Dolly's condition; approached other doctors – traditional, religious and herbal healers – for treatment. Such treatments yielded no result except a huge loss of money and time. However, Dolly's mother persistently worked hard to train up her and as a result of that labour Dolly gradually learned to walk a little, eat solid food and even to take bath and wear clothes alone.

*...Her sisters fearing that their marriage proposal will never come or break-up due to Dolly used to lock her in a dark room and even prayed for her death secretly. Such negative treatment from their other daughters towards*

Currently a rehabilitation worker of a local development organization is providing primary rehabilitation therapy to Dolly. As a result she has grown interest in household works. But her mother and sister-in-law do not allow her to do any work. Her brother and his wife love her equally if not more as her father loved her when he was alive. It can be said that her acceptance in the family has increased than the past. Her sisters fearing that their marriage proposal will never come or break-up due to Dolly, used to lock her in a dark room and even prayed for her death secretly. Such negative treatment from their other daughters towards Dolly used to pain her parents a lot. Interestingly, although her sister-in-law is not blood related but she loves Dolly the most. She has easily accepted the disability of Dolly.

Dolly is very eager to visit outside her home. But the other members of the family are afraid of allowing Dolly to go outside as she might fall victim to the evil eyes and intentions of the crooked men of the village. As a matter of fact she is also not allowed to come in front of any other man except the rehabilitation worker. Besides, the family members also felt that with coming up of age Dolly would also develop physical needs. The bad men of the society might exploit this situation. As such Dolly is somewhat forced to lead a controlled life inside the small boundaries of her home.

## Case study - 21

### Sakina whose happiness was short-lived

Mossammat Sakina Khatun was born in a very poor family in Hatia of Noakhali district. Her father, Mahmudul, is a day labourer. Nasima Begum, Sakina's mother is a housewife. Sakina is the eldest in a family of four children. The negative fallouts of poverty have always gripped the family. Life for them was never easy rather they live in persistent hardships and sufferings.

*...To add more pangs and pains to the family, her mother gave birth to another daughter with speech and hearing impairment. For giving birth to two such daughters, the community people started to see and treat the family differently. They assumed that these unfortunate events are results of sins that Sakina's parents had committed...*

By the eight months of her age Sakina's parents could understand that she was not responding to rather became shaken at sudden or high level of sounds. At a later stage it was realized that Sakina was also not able to hear or speak totally. Even they thought that she was perhaps under the influence of evil spirits. They took her to traditional, herbal and religious healers. But all their effort ended in vain. Just at the stage when they had given up hope of the possibility of finding a cure for Sakina, a doctor arrived at the village. Her parents wasted no time and immediately rushed to the doctor hoping for a 'magical cure' to Sakina's problem. The doctor examined Sakina and ascertained that she would be able to listen and speak well in future. They become extremely happy. They built up hopes and expectations again. Time passed on but no improvement was noticed to Sakina. They soon realized that the doctor gave them false hopes. They again felt shattered. Though cruel yet the reality was that Sakina would never be able to hear or speak, her condition is permanent. In fact, Sakina can make only one or two unrecognizable sounds, nothing more. She never had or is used to use hearing aid.

Sakina grew up in a very difficult condition with insurmountable barriers and obstacles. Sakina was not the only child who had disability in the family. To add more pangs and pains to the family, her mother gave birth to another daughter with speech and hearing impairment. For giving birth to two such daughters, the community people started to see and treat the family differently. They assumed that these unfortunate events are results of sins that Sakina's parents had committed.

Sakina and her sister used to help their mother in the household works. They are able to perform all the works of the house– from cooking to cleaning. The sisters also obtained skills on sewing and handicrafts. They utilize their skills to make some income. They had learned these skills from their mother. At times the sisters also worked as housemaids in peoples' houses. Though they are not able to speak or hear but they can very well communicate through gestures and expression of their eyes. The sisters used to live a routine life.

As Sakina grew up, a man of their village offered to marry her. The family was very happy and wasted no time in getting Sakina married to the kind man. The marriage brought new hopes, in fact, a new life for Sakina. She felt as if her days of sorrow and sadness had finally ended. But tragically her happiness was short-lived. With in three months of her marriage, her husband passed away succumbing to severe illness. Sakina felt devastated at the unfortunate turn of events. With tears in her eyes she had to return to her parents house where she earlier experiences odds of life so bitterly.

Sakina is now twenty-four years of age. Her life is now very painful. It's a struggle for Sakina to survive with prestige and honour. She has very little acceptance in the community. She is barred from all social events of her family and of the relatives. She is now neglected by all and seen as a bad omen. Sakina can only contemplate in isolation and ask all in her own language, what her fault was that she is judged and treated as such. She sheds tears asking, "...why won't anyone try to understand me and the pains and sadness that I suffer each day? Is it that I can't communicate or the other people who don't have the capacity to understand me or my pains?"

## **Case study - 22**

Durga absorb all shocks for a better future of her daughter

Durga was so named by her parents as she was born on the day of Durga Puja the biggest religions festival of hindu communities. She lived in a poor family of eight members. It was always difficult for the family make both the ends met everyday.

Durga has cerebral palsy from her birth. Her parents were simply ignorant of their daughter's condition and also of the appropriate interventions that could cure her. She was not taken to any doctors or rehabilitation service providers. They had however resorted to local religious and traditional healers. But there were no change to the condition of Durga. Even though Durga had cerebral palsy she had no problem intellectually. She always tried to improve her condition. Durga was even able to walk with the assistance of a thick stick.

**As Durga grew older her parents became concerned about her future, especially her**

*...Ever since her childhood Durga was always eager to go to the temple to perform Durga Puja. But ironically she was never given the chance. She has always been dropped behind to guard the house while others went to perform the Puja. The family members have no respect to the interests and opinions of Durga. She is not allowed to take decisions on her own or her daughter's affairs. Her brothers have stopped education of Jamuna...*

**marriage. They were in anxiety and worried that she will not be able to get married due to her disability. Her parents decided to get her married to whosoever possible. Finally, they were able to find an old and sick man who had agreed to marry Durga.**

Durga cared and served her husband to the best of her capacity. After one year of their marriage they were blessed with a beautiful little daughter. She was named Jamuna. As Jamuna was growing up, disaster struck the family. Jamuna's father died when she was only four. Durga and Jamuna were alone and not in a position to sustain by themselves. They had to look for shelter.

Durga's father was then very sick, virtually immobile. He stayed with his son, Gopal. Durga's mother had moved to her other son living in India. Her brothers did not warmly welcome Durga and Jamuna. They were reluctant to allow her to stay with them. However, Gopal took her in his family.

Gopal is married and has a family. Shelter in her brother's family did not come without a price. Durga has to perform all the household works. It is not easy, especially because it is difficult for her to keep physical balance. Regardless of all her efforts she has to hear the persistent scorns of the family members and face ill behaviour. Durga is saddened by the mistreatment she receives. She, however, does not express it, except tearing in hiding. But

she cannot escape from the eyes of her daughter. Jamuna intensely feels the pains and sufferings that her mother experiences. Jamuna now eagerly waits in anticipation for that bright day in the future when she would be able to remove all the pains and pangs of her mother.

Ever since her childhood Durga was always eager to go to the temple to perform Durga Puja. But ironically she was never given the chance. She has always been dropped behind to guard the house while others went to perform the Puja. The family members have no respect to the interests and opinions of Durga. She is not allowed to take decisions on her own or her daughter's affairs. Her brothers have stopped education of Jamuna.

Durga is now thirty-eight. Her physical condition is severely deteriorating. She is worried about the future, especially for her daughter. Despite all her worries and anxieties, she has not stopped dreaming of better days. She longs for a time when her daughter will once again be able to pursue her education, when she would be able to get a job and build a career, when she would look after Durga. Her dreams give her strength to face the adverse realities with new courage, though she does not know if her dreams will ever be realized.

### **Case study - 23**

#### **Renu felt dejected, but not defeated**

Rehana Begum Renu is the youngest of the eight children of her parents. She was the dearest child of her father who was a very poor man. Poverty was pervasive in the family. They lived in the village of Char Aicha under Charfession Upazilla of Bhola district.

*...Ultimately, she found herself alienated and isolated. But she had two little goats as companion. Renu and the little goats seemed to communicate mutually. These pets seemed to understand Renu's feelings and expressions better by observing her face, what no man could do...*

Renu, 35, is a speech and hearing impaired person. She had a normal birth and had no problem in her physical development. But she was not able to say any sensible words, even at the age of one. Her parents became worried about it. But just then, it seemed that Renu was attempting to pronounce a few recognizable words like 'Ma (Mama)', 'Baba (Papa)'. Her parents presumed that perhaps their daughter was a slow learner and would be able in the future to speak like others. Years passed on but no progress was marked in the development of Renu. At this stage they detected that she could not also hear properly. Her parents failed to realize that lack of hearing power could also act as a barrier to one's speech-skill. However, they could finally realize that their daughter has problems both in hearing and speech capability and she might not be able to hear and talk permanently.

**Life slowly started to become unpleasant for Renu and her mother. Most people rebuked Renu's mother for giving birth to a 'deaf and dumb' child. The local boys and girls teased and called Renu by bad names. Renu's mother was bewildered and could not find the proper ways of dealing with such negative attitudes and environment. She was very embarrassed and disheartened at the disability of her daughter. She started to consider Renu as a disgrace of her womb and also as a burden to the family. Renu could also realize the feelings and negative attitudes of her mother. She felt sad but could not express that in words. But the only positive thing for Renu was her father**

**who happened to be very caring and loving to her. She was the most loved child of all his children.**

Through Renu could not hear or speak but she could understand and express almost everything by signs and gestures. No one thought Renu could study, '*...she can not hear or talk, how can she study?*' this was the common perception about Renu. Her parents also had the same understanding. As such, Renu was not provided any opportunity to study. Besides, the local school had no provision or the 'know how' in providing education to a speech and hearing impaired child.

Renu's parents also thought that she would be unproductive and unable to do anything. She was not assigned any task of the domestic chores. Ultimately, she found herself alienated and isolated. But she had two little goats as companion. Renu and the little goats seemed to communicate mutually. These pets seemed to understand Renu's feelings and expressions better by observing her face, what no man could do.

Though Renu could not talk, she was very attractive; everyone liked her at first sight. As she reached eighteen, her parents wanted to get her married. As she was very beautiful, it was not difficult. An aged rich man of the neighbouring village married her. Renu's parents were very happy and relieved at the marriage of their daughter. They presumed that Renu would be happy at her in-law's house as they were expected to be aware of the speech and hearing impairment of Renu. But in reality nobody in her in-laws house except her husband knew the real fact about Renu. Soon they could know that the newly wedded bride could neither hear nor speak. This came as a tremendous shock to the whole family. Following this disclosure the situation drastically worsened for Renu. Her father-in-law, mother-in-law and all other relatives started to harass and call her by derogatory names. Renu felt hurt and pained. She used to secretly shed tears, in pangs, pains and helplessness. Soon the family members started exerting influence on her husband. They used to complain frequently on false issues. Renu loved her husband very much. But all her love and care could no longer prevent her husband from developing dislike to her. She was absolutely heartbroken and helpless. Regardless of all her efforts to defend her and prove her innocence she failed. She could not gain over the hearts of her in-laws. Failing to withstand the constant persuasions and influence of his parents, Renu's husband divorced her. Renu came back home heavy heartened, defeated to the forces of evil. She has no hope for the future.

Renu used to spend most of her time in despair and sadness. But she did not want to be a looser. She started to gather strength from all her suffering and prepare for the life ahead. Renu got inspirations from the struggle of her old father, from the labour someway and the commitment her father put in keeping the family together. She could no longer keep herself inactive and nonproductive economically. With the help of her father she now rears a few poultry. She puts all her efforts and sincerity in raising them. The poultry not only contributes in the family income but also give Renu companionship.

Renu has not married for the second time. She has no such intention. Renu realized that every life has a purpose and role in this world. Despair and tears will help no one. With courage, sincerity, commitment and honesty wonders could be achieved. A woman must create her own future and not be dependent on others. She now firmly believes that she can overcome all barriers and obstacles and build a prospective and beautiful future for herself.

### **Case study - 24**

Masurun robbed of the hopes and freedom



Masurun Akhter Lucky lives with her parents in Badda, Gulshan. Her brother, a driver, maintains the family. Lucky was born and growing up normally amidst love and care of her family members. But the happy days did not last long. Her happy world transformed into a sad one when she became sixteen. She is now physically disabled; unable to walk on her feet, she now uses a wheelchair for any sort of locomotion.

In 1998, when Lucky was a student of class nine at the Alahtunnessa High School and College; a tumor was diagnosed on her spine that was gradually causing paralysis to her legs. Lucky was admitted to Dhaka Medical College Hospital where she had undergone surgery. Unfortunately she did not gain enough strength to her legs so as to walk herself. The doctors advised her to be taken back to her home and regularly do some physical exercises as demonstrated by them. But on return to home the condition of Lucky deteriorated severely. She started to have regular seizures as a result of which her legs used to bend like a bow. After a few months, upon an advice

*...One of the main barriers that Lucky faces at her house is that it is not wheelchair accessible. Moreover, if she uses the wheelchair, she will not be able to move by herself. For most of her activities Lucky has to depend on her mother...*

from a doctor, Lucky was taken to Centre for the Rehabilitation of the Paralyzed (CRP), Savar. The center began her treatment again. Consequent upon regular treatment at CRP senses returned to her legs but she was still unable to walk. She was given a wheelchair for movement. Now Lucky is absolutely dependent on the wheelchair for movements. Currently she is taking a one-year long training course on the repair of electronic equipment at the center.

With her disability Lucky no longer wants to mix with her friends and relatives, she rather avoids them. She also does not like going to social events; she feels pain for not being able to walk. Lucky suffers from inferiority complex. She can no longer think of celebrating like the past in different family and social events.

One of the main barriers that Lucky faces at her house is that it is not wheelchair accessible. Moreover, if she uses the wheelchair, she will not be able to move by herself. For most of her activities Lucky has to depend on her mother. She does not at all like to bother others for her own needs. As such most of the times Lucky keeps silent even if she needs something. She fears that others will become irritated at her for requesting for assistance all the times. Lucky also feels sad due to the immense financial burden that her brother has to shoulder to arrange for her treatment. But Lucky and the family have no other choice, as there is no other earning member in the family.

Lucky blames fate for her current situation. Once she had freedom but now she feels as if she is shackled, being dependent on others for all her requirements and needs. Under such a negative circumstance, Lucky feels acquiring education would only allow her to live a better life. She wants to go back to the schools once again. But as her classroom is in the second floor of her school, she is unable to attend her classes. Besides, the school authorities are not willing to take initiatives to add accessibility features allowing Lucky to attend her classes, which could enable her to fulfill her dreams. She is now further depressed with numerous questions razing in her mind. "Why my school would not add accessibility features? Will I not be able to study? Will I not be able to meet my dreams of acquiring higher education? Will my future be ruined because of lack of opportunity?", she stared and contemplated seeking answers.

Two years had since passed; Lucky did not have the scope to study, by now she has lost her dreams. Now she dreams again, but of a different kind. Lucky now wants to find employment to earn money and contribute to the family income and reduce her dependency. But she is worried, would her dream be shattered like the previous one. She feels it is most likely that her dreams would remain unfulfilled and she will remain in this world without her freedom and liberty.

## Case study - 25

Mita: Reality is far from dreams!

Mita, 16, is an adolescent girl. She now lives in Rajshahi city. Her father runs a small shop. The whole family was very happy at the birth of Mita. But dark clouds soon hovered over their happiness. Mita had pneumonia while she was only two month old. She was so severely affected by pneumonia that the relatives and neighbours thought that Mita would not survive. They wanted to bring her to Rajshahi Medical College Hospital. But her mother did not agree. A doctor was called to the house for medical treatment. As a result of the treatment, Mita recovered from the illness but she was never like other children of her age group.

Mita grew up amidst profound love and care of her grandparents. But her development phases were not at par corresponding to her chronological age. It took her two years to have balance and control of her neck, seven years to sit with support.

*...It is fact that Mita has Cerebral Palsy, but it has not adversely affected on her intellectual capacity or on her sensory of feelings. After getting the wheelchair Mita now attends and participates in different meetings and seminars on disability issues. Sharing knowledge and experiences in those meting Mita now realizes that she is not alone but there are many more like her with similar problems...*

As Mita grew up, she used to be kept seated with support. But by sitting in that manner days after days, she developed deformity slowly. A side of her chest becomes enlarged abnormally. Her two legs virtually becamre joined. She was taken to an orthopaedic surgeon. Mita was advised to have a surgery. After long considerations, Mita's parents collected money from their relatives and performed the surgery. But unfortunately her condition worsened after the operation. Her left knee developed permanent contracture. The position of her legs remained unchanged. The worries and anxieties of her parents increased as no improvement happened to their daughter. Gradually Mita's condition worsened and she developed further physical difficulties. Mita had to lay on the bed continuously. She has to do her toileting on bed. Her mother always cleaned her. Mita has to be carried from one place to another.

A rehabilitation worker of a development organization identified Mita. They arranged a wheel chair for her. The rehabilitation workers counselled the family members of Mita and explained that she will never be cured and develop like others of her age group. The whole family became sad with sorrow. But finally they have accepted the hard and cruel reality of Mita.

Now with the wheelchair the barriers that Mita encountered had subsided. She can now move around. Wherever there is a scope Mita spends her time listening to music and watching television. The neighbours have never treated Mita well. The harsh treatment of the neighbours also pains and hurts her parents. Despite all the negative attitude of the community the mother is regularly providing care to Mita according to the advise of the rehabilitation worker. It is fact that Mita has Cerebral Palsy, but it has not adversely affected on her intellectual capacity or on her sensory of feelings. After getting the wheelchair Mita now attends and participates in different meetings and seminars on disability issues. Sharing knowledge and experiences in those meting

Mita now realizes that she is not alone but there are many more like her with similar problems.

Mita often felt depressed and frustrated contemplating over her situation. *She asks herself as to who is to be blamed for her condition. She does not want to blame herself or accept it as her fate but rather accuses God. She wants to know what was her fault or crime for that she has to suffer like this.* She too would like to be married and have a family. But she knows this will never come true. Her mother on the other hand blames herself. She thinks that perhaps Mita has been so punished by divinity for a sin that she might have unknowingly committed.

Mita will perhaps never be able to perform the essential activities of daily living on her own. She would have to remain dependent forever. Now she has her mother to look after her, but what will happen after the death of her mother. Questions like this always bother her parents. They now regret that had they knew it earlier as to how to take care of children with Cerebral Palsy, perhaps, then the condition of Mita would have been much better than what it is now.

## Case study - 26

### Shilpi is proud to be self-sustaining

Shilpi Rani, 18, is a girl from a simple family in the village of Khansama in the district of Chittagong. Her father, Lal Mohan Nath is a homeopathic doctor. She is second in a family of five – 3 sisters and 2 brothers. Her eldest sister is married; the younger brothers and sisters are studying. Shilpi had completed her education up to standard Class V. An accident causing paralysis of her two legs has stopped her education.

*...She is impressed and happy at the accessibility features in the center and the acceptability that she has received at the center. At least no one is over curious about her disability. The environment at the center has rebuilt her self confidence. But at the same time she is not without despair and hopelessness. At times she deeply feels the isolation from her family members, for which she is also partly responsible, this feeling grows a sense of guilt in her...*

When Shilpi was twelve, she went to her maternal uncle's house. One day while playing she climbed up a tree. But misfortune followed her, she slipped and fell to the ground – a fall that had changed her life forever. It made Shilpi; a youthful girl, full of zeal; a lifeless immobile identity. Shilpi had lost sensation from her waist downward; both of her legs became immobile. She was rushed to the Chittagong Government hospital. She stayed there and received treatment for twelve days. She was then transferred to the Centre for the Rehabilitation of the Paralyzed (CRP) in Savar, Dhaka. No improvement of her physical condition was observed even after six months of treatment. The doctors there no longer expect that the legs of Shilpi would be cured. The treatment at the center had to be borne by Shilpi's family. Her maternal uncle shouldered most of the expenses. During her stay at the Centre Shilpi had also received skill training in tailoring. She now uses a wheelchair for mobility. To her the wheelchair has compensated for her legs.

On completion of her treatment at CRP, Shilpi returned to her village home. She stayed there for four years. But she did not at all like to stay there, as there was virtually no accessibility or scope for free movement with her wheelchair. This had always hampered her attempts to participate in social events, especially visiting her relatives and friends. On the contrary she was getting irritated at the over curiosity that people were showing to her

disability. She was so annoyed that she started to avoid all. Shilpi began a life in isolation and seclusion. But her relationship with her parents, brothers and sisters was always very close and bonded.

In 1999, Shilpi returned to CRP to join as an employee. After 1999 she had not visited her village home too many times. It is not that she did not have the opportunity; she did not want to go. Shilpi earns a considerable amount of money from the job. She spends the money on or for her own, as she does not have to spend anything for her family. Shilpi is currently staying at the hostel building of CRP. She is impressed and happy at the accessibility features in the centre and the acceptability that she has received at the center. At least no one is over curious about her disability. The environment at the center has rebuilt her self-confidence. But at the same time she is not without despair and hopelessness. At times she deeply feels the isolation from her family members, for which she is also partly responsible, this feeling grows a sense of guilt in her. Shilpi presumes that she will not perhaps get any cooperation or assistance from her family members and relatives in the future.

Shilpi does not feel like marrying in the future. Her sole aim is to perform well in her job and eventually build her career. Regardless of all her miseries and pains, Shilpi still considers her lucky and happy that at least she will never have to be dependent on others.

### **Case study - 27**

#### **Irresponsiveness of a doctor ruined the life of Margina**

**Margina, 40, is the name of an unfortunate lady. She lives with her father Sitabadi Sheikh at Damdardi village under Modhukhali Upazilla in Faridpur district. She is the eldest of six siblings. Her father is a poor and landless farmer. Poverty is a part of their life.**

*...If she had a life partner, it could perhaps be easier for her to have social security in the society. Unfortunately, no body considered accepting her as wife due to her disability. She can do all the work of her own house but no body wants to acknowledge her ability. She had a dream of having a family like any other normal girls but reality proved to be too cruel to her and social handicaps acted as obstacles to her dream being true ...*

**At the age of eight she had high fever. Observing her critical conditions Margina's father became puzzled and went to call a doctor. But the irresponsible doctor didn't response to the request of the poor father and sent an assistant instead. The assistant made wrong treatment as he failed to diagnose the disease and it causes. As a result the fever didn't subside easily. After long time when the fever subsided Margina realized that she couldn't see any thing. She, thus, lost her vision forever. When Margina's father went to inform about the situation of his daughter to the doctor, the doctor begged pardon to the father and tried to free himself from the accountability. Since then Margina has been living with her father, fully dependent on others. Margina's world has been confined within the boundaries of her father's small home.**

**Margina lost her vision at schooling age. She did not get any opportunity to enter into a school for study. Though there was an opportunity to get education in adult education centers but the system and also the curriculum of those centers were not**

suitable for visual impaired person like Margina. Now at this age she has no chance of getting education at all.

Every time she has to struggle against the social obstacle. Due to her limitation she always becomes afraid of coming outside her house fearing abuses by the crooked ones of the society. If she had a life partner, it could perhaps be easier for her to have social security in the society. Unfortunately, no body considered accepting her as wife due to her disability. She can do all the work of her own house but no body wants to acknowledge her ability. She had a dream of having a family like any other non-disabled girls but reality proved to be too cruel to her and social handicaps acted as obstacles to fulfill her dream being true.

When Margina contemplates about herself, she finds herself filled with sadness, sorrow and frustration. She has never been able to contribute remarkably to her family due to her limitations. Naturally, her family members consider her as a burden rather than an active member. But in reality Margina doesn't like to pass an inactive life. She cooks and does all other domestic chores to the best of her ability. As a conscious citizen, she has voted in different elections too.

She is lucky that her father is still alive. But at the same time she is afraid thinking that in the absence of her father she might not be allowed to stay in her brother's family. This fear of future uncertainty has motivated her to be self-reliant. She received some skill development training from a local NGO, which is working for the rehabilitation of persons with visual impairment. The NGO has also provided her with a capital on credit. She has been provided with a white cane that she found useful in her everyday movement.

She sometimes ponders over and tries to find out what she desires to be and what she has actually gained. But she can't reach at any concrete conclusion. She considers that the neglect and the wrong treatment of the doctors alongside the ignorance of her parents are responsible for the miseries of her life. Her parents also blame themselves for the condition of their daughter and suffer a lot of mental anguish and frustrations. They regret that if they had lands or wealth they could have been able to get their daughter married.

### ***Case study - 28***

Salma fought disability with courage

Salma Akhter, 20, the eldest daughter of Md. Abul Kalam Sardar lives at Char Kamolapur of Kotoali Thana in Faridpur district. The family has six members including the parents and a grandmother. Salma has a sister and a brother. Salma was born normal both physically and mentally. She grew up normally and began her study like others normal children. As she was meritorious, her father wished that she should study in medicine. She was doing well in her studies at grade VIII as if to fulfill her father's dream.

One day while she was riding on a bicycle with her uncle, unfortunately their cycle collided with a speedy truck and both were seriously injured. The injury of Salma was very serious. She was immediately admitted into a medical centre. But her injury was

so grave that her left leg became severely mutilated. Even medical treatment continuous of three months, failed to save her right leg from gangrene. The doctor advised to amputate her right leg also. In a bid to save her leg, her parents took her to the "Pongu Hospital" in Dhaka. The doctors there also gave the same opinion. But her parents eagerly plead to save her right leg. The doctors then made plans for conducting plastic surgery. Her mother Jesmin Begum donated her tissue for the plastic surgery. Ending a four months long treatment course, Salma returned home partially cured. Doctors advised her mother to continue some exercises. As her infection wasn't fully cured, she felt serious pain while taking the exercises. Being moved by the severity of the pains, her parents discontinued the exercises advised by the doctors. As a result her leg became stiff and straight and she couldn't bend her knee. Since then Salma started to use crutch for movement.

*... About two years back, Salma's father arranged marriage for her to a man less educated than Salma with the promise of giving him a job. But this marriage did not work. Being unable to accept the disability of Salma he divorced Salma after six months of their marriage...*

Salma's parents were ready to donate their physical organ and also the cost involved to find a cure for their beloved daughter. Salma's father spent a lot of money as treatment cost. He had to even take loan.

Following the accident Salma had to discontinue her studies for about one and a half year. Besides, her mental strength was also severely shattered. However, her parents encouraged her much to continue the study. Alike the past Salma couldn't pay much attention to her study. But she had not lost her self-confidence. Realizing Salma's interest in and zeal for education and also her parents sincerity to this effect, the neighbours, friends and relatives helped them. Salma could sit for H.S.C examination due to her self-confidence and others encouragement. The crutch is now her walking partner. Salma is well appreciated by all as she used to be before the accident. Here, her disability has not been a factor. Her friends like her so much that they help her very much in all respects.

About two years back, Salma's father arranged marriage for her to a man less educated than Salma with the promise of giving him a job. But this marriage did not work. Being unable to accept the disability of Salma he divorced Salma after six months of their marriage.

However, after a year of her divorce Salma got married again to one of her neighbour who proposed her on his own will. Now the couple is passing their conjugal life happily.

Salma started to learn different skills along with her study. She also became a member of a local organization working with disability. Comprehending Salma's zeal for doing something on her own they (the authorities of organization) admitted her into a tailoring college. Salma's father also engaged a private tutor for helping Salma in tailoring lessons. On successful completion of the training, Salma has been provided with five thousands taka as loan by the said organization. She bought a sewing machine and some clothes and started tailoring on commercial basis which is now yielding her an income. Appreciating her courageous steps the local people have decided that they would make their clothes only from Salma so as to facilitate her to be self-reliant.

Salma is no longer depressed. She knows that people with disabilities do not necessarily have to sit at home idle; if they were well trained and given the opportunity. She has a dream to complete homeopathy course and to serve the people. This will also meet the dream of her father of her becoming a doctor.

### **Case study - 29**

Siblings cure treatments pain Beguni most

Beguni belongs to a poor but large (of eight members) family. Her father is a petty businessman. Financial hardship appeared to be a regular matter for their big family. In fact, they live in poverty.

After a few months of Beguni's birth her problems in hearing was identified. Her father sought treatment for the daughter from local allopathic and homeopathic doctors. Such treatments yielded no result. Despite poverty, the family continued efforts to arrange treatment of Beguni. The family spent Taka ten thousand for the treatment. As there was no result noticeable, they finally gave in and stopped treatment of Beguni.

*...The neighbours in the community not only blame Beguni but also her parents for the situation. They even comment that Beguni's sufferings are the results of sins committed by her parents. Beguni's parents are in a way forced to keep her hidden because of these negative attitudes. She is not even allowed to meet with the relatives*

However, at a later stage Beguni's parents came to know that her condition was permanent and no medicine would cure her. Knowing these realities, the parent now repents for their ignorance and blamed the local doctors who gave false hopes. They have also realized that there is no 'magical cure' to hearing difficulties. Had they been only advised in right direction they could have sought rehalitative supports for Beguni. But now they have neither the financial capability nor a chance to set things right so far Beguni's lost hearing capacity in concerned.

Currently Beguni has no importance or value within the family. She is neglected and discriminated; she is not given clothes or other essential things like her brothers and sisters. The brothers and sisters do not behave properly, not to say affectionately; with Beguni. They just maltreat her in a rather inhumane way and treat her like a animal calling her 'Tommy'. When they take meal they don't call or allow Beguni to sit with them. They always maintain a distance from Beguni fearing that they too would become disabled if they come in touch with her. Such cured dealings received from the siblings hurts Beguni much but she has no language to protest or depict the pains she feels.

Such discriminating behaviour from the family only encourage the neighbours to follow the suit to Beguni. They not only avoid her but also ridicule her in many ways. The neighbours in the community not only blame Beguni but also her parents for the situation. They even comment that Beguni's sufferings are the result of sins committed by her parents. Beguni's parents are in a way forced to keep her hidden because of these negative attitudes. She is not even allowed to meet with the relatives who visit their home.

Beguni has now lost all her self-confidence, mental strength, self-esteem and the will to struggle and fight for survival. She fears that she will have to live as a burden for the rest of life in her parents' family. She contemplates why should she suffer if her



sufferings are the result of the sins committed by her parents. As she is not educated or has no vocational skills, she cannot make any financial contribution to the family. Beguni's opinion has no value in the decision making of the family. She is simply ignored or overlooked.

No efforts were taken from the family for the rehabilitation of Beguni. Her hearing loss was never measured; as such no hearing aid was ever given to her. Beguni has been neglected at every stage of her life. She is really afraid of her future. Beguni and her parents always worry if she will ever be married, and even if she is married how will her in-laws treat her? *Beguni is now at a crucial stage of her life; the next few years will decide the final shapes of her life.*

**Mayman looks forward only for her son only**

Mayman Begum, 32, lives in Baro Beltala village in the district of Tangail. She is currently thirty-two years of age. Once She had an accident in her childhood that resulted to mild degree of physical disability.

**Mayman was born in a poverty stricken family. Her father was a beggar and mother a housemaid. Her parents never thought of sending Mayman to school, rather they engaged her to be a housemaid like her mother. Besides, Mayman was also engaged to do a lot of their household works. One day Mayman had to go to the surrounding forest to collect fuel woods. She climbed up a tree and unfortunately fell down. She suffered severe injuries on her leg and body. Her parents could not provide proper medical treatments due to their poverty. Instead they resorted to traditional and religious healings. But these treatments had no positive effect on Mayman's condition and there was no result. Her condition deteriorated due to inappropriate treatment and one of her legs became deformed. Since then she has limping.**

Mayman, however, continued to work as housemaid. In one such house she met a man

*...Soon they got married and had a male child. But unfortunately the feelings of Majid towards Mayman got reversed. Majid was no longer able to accept the disability of Mayman. He felt embarrassed when people teased him pointing to Mayman, more so to her disability. And in one fine day Majid forced Mayman out of their home. She felt devastated at the cruelty of this harsh world. She*

named Majid. He also used to work in the same house. They developed likings for each other and ultimately fell in love. Soon they got married and had a male child. But unfortunately the feelings of Majid towards Mayman got reversed. Majid was no longer able to accept the disability of Mayman. He felt embarrassed when people teased him pointing to Mayman, more so to her disability. And in one fine day Majid forced Mayman out of their home. She felt devastated at the cruelty of this harsh world. She returned back to her parents' home. They too were at a loss in the face of such situations. Her parents desperately tried to get her married again. Mayman felt helpless at these perplexing situations. "... I felt as if I was an object, a lifeless thing with no feeling, with no right to decide about my own life, my life was in the hands of others", said Mayman. Her parents soon got her married for a second time with a very old man. But she had no happiness and her second husband also died leaving Mayman alone with her son from the first marriage.

**Mayman still lives a life in pangs and pains. She is now more dependent on others than before. The condition of her damaged leg is further deteriorating rapidly. Now she cannot do things on her own. She has to seek help from other more frequently. She is afraid, very afraid of the future, but her only hope is her son, whom she considers as her only resort to leading a life.**

**Mayman has reasons to feel frustrated. "I firmly believe that many people with disabilities are deprived of the opportunities and rights simply due to negative attitudes of the society. Had the people with disabilities been given the appropriate training, education, and environment he/she could also be able to contribute like any other non-disabled persons. And would not have to live as a burden of the family," exclaimed Mayman.**

### **Case study - 31**

Do the people with lost vision have a future?— asks Fatema

Fatema, 38, lives with her father in Hatia. She has visual impairment. Her father is old and is unable to work to earn a livelihood. Fatema along with other members of the family works hard for bare subsistence of life.

***...Fatema is socially very much neglected. She is often called by bad names after her disability. Despite her abilities she does not get acceptance or recognition from her co-workers. Fatema feels hurt and psychologically***

Fatema was only one year old when she lost her vision. One day she fell down from the lap of her older sister and received injury on her head. Small particles like sand had also entered into her eyes. At a later stage she felt acute pain with very high fever. As Fatema's condition did not improve, her mother sought treatment from the village doctor, traditional and religious healers. She treated Fatema with the different medicines and Holy-water that the healers had given to her. But nothing did work. Her left eye started dripping continuously resulting in severe pains and it became rough & closed. Eventually, Fatema lost her vision of the left eye. However, Fatema was able to perform the activities of daily living with vision in the other eye. But unfortunately this eye also developed problems, which resulted in limited vision. At this her parents got scared and become serious for her treatment. They took her to a medical college where the doctors prescribed her treatment. But the family could not afford the treatment because of their abject poverty.

Fatema was once married when she was twenty-one. But the husband deserted her after a year. He did not make any contact with her for many years. However, the man divorced Fatema citing her visual impairment as the main cause. Since then Fatema has been living with her parents.

Fatema could not pursue her education due to poverty. She had to contribute to the family in whatever way she can earn an income. Currently she works as a day labourer. Fatema has to earn for her self-survived as well as she has to contribute to the family in whatever way possible.

Fatema is socially very much neglected. She is often called by bad names after her disability. Despite her abilities she does not get acceptance or recognition from her co-workers. Fatema feels hurt and psychologically depressed when she has to encounter such negative situations. She often questions: If the world is only for the people with vision?

Regardless of all the pains and sufferings that Fatema had experienced and encountered in her life, she still dreams of having a family. She feels that it is very difficult to live normally in the society without a husband and children. It is very essential to have a family to self-guarded oneself against the evil intentions of the bad men of the society. But she does not know if she will ever be able to transform her dreams into reality.

### **Case study - 32**

Let Tamanna imbibe others

Tamanna Siddique, 31, is a committed lady. They are three sisters and two brothers. Her father is a retired Government service holder and her mother a housewife. Tamanna was born in Islamabad, Pakistan. Now she lives in Dhaka. She had no disability at birth. While she was 3 years old she had high fever. Her parents failed to realize that it was not a normal fever. She was not able to stand up even after the fever had subsided. They then consulted a doctor about Tamanna's condition who diagnosed that Tamanna had polio. The family was deeply shocked but did not refrain from providing essential medi-care to Tamanna. Physiotherapy was given to Tamanna regularly while in Islamabad as advised by the doctor.

*... Saibal firmly believes that he did not marry a disabled woman but a woman with a good heart. Tamanna consider it as her best achievement...*

After the War of Liberation in 1971, Tamanna's family returned to Bangladesh. In Bangladesh they stayed for some days at Feni. There a local herbal healer assured them that he would be able to cure Tamanna. Taking the assurance in confidence Tamanna's parents had wasted a huge amount of money in quest of a magic cure. Anyway, the disillusionment was over and they finally came to Dhaka. They again started physiotherapy for Tamanna in a local 'Children Physiotherapy Centre'. On application of regular physiotherapy Tamanna was able to walk using a special shoe. But the standard of such special shoe that was then available in Bangladesh was not of good quality. Tamanna, however, stopped using the special shoe as she did not feel comfortable with it. Currently, she does not use any assistive device. Though she encounters difficulties still she can walk without any devices.

Tamanna started her schooling at 'Kisholay Uchho Biddalay' in Dhaka. Her parents rented a house very close to the school. Tamanna spent her childhood in isolation, it not in alienation. She always liked to stay alone away from others. She had some two-three friends at her school but she never played with them. But from her very childhood she was very attentive in her studies. Tamanna studied at Kisholoy upto Class II. Thereafter, she moved to 'Kallayanpur Uchho Balika Biddalay'. Most of the teachers of the school treated her equally and did not differentiate or discriminate her on disability count. However, a few in the school treated her differently. Tamanna could apprehend that she was treated negatively. But her self-confidence made her mentally strong which helped her to overcome such negative or unfriendly environment.

Tamanna passed her S.S.C. and H.S.C in Second division. She could not enjoy her college life like others. It was very difficult and painful for her to walk even a short distance. Besides, some people used to pass bad comments or starred at her when she walked on the street. These made her feel very uncomfortable. But these could not create barriers to her education. Her self-confidences, merit, interest in education and the inspiration received from her family helped her success in life. She completed her graduation from the 'Eden University College, Dhaka'. She had the intention to do her Masters from Jaganath University College. But due to accessibility proble's at the college she had to give the plan up. Initially, she felt depressed for this. But soon she enrolled her in to the LLB course in a city law college. She also successfully completed the first part. While studying the second part of the law course she joined with a Community Based Rehabilitation (CBR) implementing organization as a volunteer. In 1995, she had the opportunity to take a two-month long training course on CBR in Indonesia. As she got deeply involved with her work she could not continue her law education.

She formally joined the organization in January 1996. The organization was located at Savar. She joined first as an Assistant Coordinator and was subsequently promoted to Associate Coordinator. Tamanna is entrusted with training there. *Some body thought she got*

*the job to a favour as a disabled person since the organization works on disability issues. They have been proved wrong because she belied them proving her worth & competence through job-performance. Tamanna is very happy with her job. She feels proud for being able to offer services for her fellow disabled community. Her dreams have come true to engage herself in the services of those unfortunate persons with disabilities.*

**Engineer Salahuddin Saibal joined the same organization in March 1997. Tamanna met him for the first time here. Their initial relationship turned into an affair and finally culminated in marriage. Saibal's family did not initially approve the marriage. It was a normal reaction. No in-laws in the backdrop of Bangladeshi perspective would be willing to have a disabled woman as a daughter-in-law. Besides, they were also apprehensive of the negative attitude that they would have to encounter from their relations and community people. But as Saibal was firm in his decision, they could finally tie the knot. Anyway, Saibal's parents deserve praises for finally accepting Tamanna as their daughter-in-law in good grace.**

Saibal firmly believes that he did not marry a disabled woman but a woman with a good heart. Tamanna consider it as her best achievement. Saibal has recently joined an International organization working on disability issues.

As Tamanna is the eldest, her opinions and suggestions are valued with importance in the affairs of her fathers' family. But she hardly participates in social activities. She feels uncomfortable in places where there is a large gathering of people apprehending that some body may make negative comments. *She at times feels frustrated because despite being successful in life she still has to encounter so much of negative treatment that act as barriers in her everyday life.*

**Tamanna prefers to lead a very simplistic life. She firmly believes that her dream will come true, because she enjoys love, care and support of Saibal. Tamanna considers herself much happier than most other disabled women. Tamanna's life could also have been full of sorrow, pain, hardship, frustration, neglect, seclusion and depression like many other disabled women. But her self-confidence, commitment and support from the family, especially that of Saibal has helped her to be established in her life. And Tamanna now intends to inspire other disabled to gain this confidence and commitment so that they can also be equally happy in life.**

### **Case study - 33**

#### The unanswered questions of Nasima

**Nasima is a speech and hearing-impaired girl aged sixteen. Her father, Kadir Mia, is a poor day labourer. Nasima is considered a burden for the family. She was not a disabled by birth. When she was a young child, she had high fever. The local doctors and the religious healers treated her. But the fever did not subside and ultimately turned into typhoid. When the fever had subsided, it was already too late for Nasima. The typhoid left heavy marks on Nasima who subsequently lost speech and hearing sensitivity. Her parents feel guilty for not seeking appropriate treatment. Ignorance of her parents and the lack of medical facilities changed Nasima's life profoundly. However, Nasima mastered the techniques as a theory of necessity; to communicate by signs and body gestures to express her needs and demands and to some what communicate with others, though partially.**

Nasima has been deprived of the scope of education. Her parents had not considered education for her as she was a hearing and speech impaired person. Though Nasima cannot hear or speak, but she is very intelligent. Her senses too are very sharp.

**Nasima is deeply hurt and pained whenever she is mistreated, ridiculed or scorned by her family or community members. She wants to play with others of her age group, attend social and family events; but none has the willingness to understand her hopes and aspirations, they rather maintain a distance and avoid her. As such her desires/wishes are never materialised.**

*...Nasima has to work as a housemaid to contribute to the family income. But sadly just because she is disabled nobody acknowledges or appreciates the work that she performs. Although, she is contributing in whatever way and amount she can to the family income, yet she is not valued at all...*

As the financial condition of her father is very bad, Nasima has, for her self- survived as well as for the family, to work as a housemaid to supplement to the family income. But sadly, just because of her disability nobody acknowledges or appreciates her work. Even as a contributor to the family, maybe in a very small way; Nasima is not valued by the family equally.. Her peers also do not accept her. As such the world of Nasima has been restricted. She seldom goes outside the boundary of her home. But in her employer's house, whenever she gets scope, she watches television.

From her very childhood, Nasima was not able to mix freely with her peers. As she could not talk, her peers were unwilling to play with her. Since she is being deprived of her rights in the home she is also not accepted by the community people. These make her very obstinate. Nasima blames destiny for her ill luck.

Nasima's parents always worry about her future. They fear that perhaps no one would be willing or interested to marry Nasima. But Nasima continues to live with her dream. She is seeking the assurance that some one will always be responsible in taking care of her and ensure her treatment. Besides, she strongly believes that if her ears are examined and hearing aids are provided, she would be able to hear. Perhaps, she would also be able to speak a little. And when others will able to understand or communicate with her she will have the scope to get married. She will have a nice husband and a great family. These are Nasima's dreams – dreams that she has been nursing since her adolescence. But till date no initiative has been taken by any one to fulfill her dreams. Her father does not have the financial ability to help her daughter. Hence, would Nasima's dreams remain unfulfilled? It is big question to posterity. The innocent face of Nasima stares at the skies in quest for an answer that only God knows.

## **Case study - 34**

### **Anita: A victim of exploitation**

**Anita is a thirty-one year old lady. She has had severe level of hearing impairment ever since her birth. She was born as a premature baby on the eight month of her mother's pregnancy. When her impairment was identified, her parents sought to various kinds of treatment. But all their efforts resulted in no positive change. Her level of impairment remained the same.**

*... Anita often sheds tears in pain and sorrow. She is able to comprehend life around her but she feels pain thinking that no one can understand the pains and sufferings that she has been experiencing though out her life ...*

Anita lives in a family of seven members. Her family did not accept her disability. They often discriminated against her. *In her family she had to encounter a lot of barriers and negative treatments. All the children were sent to school except Anita. Anita's ordeal did not end only in discrimination and deprivation of her rights by the family. There have been instances of exploitation of her impairment and disability.* The family received a grant of Taka five thousand for Anita from a local development organization. But very little amount was spent for her, said Anita.

Anita gradually grew up from childhood to adolescence and then to adulthood. She started to have dream of having a family. But a cruel incident had shattered her dreams. Exploiting her inability to communicate, some bad men of her community had repeatedly abused her sexually. She tried to tell her horrific experiences to her close ones. But no one paid heed to her cries. *Instead of seeking justice for the wrong doings her family kept it hidden. They did not know what else could have been done. They were worried that if these news were disclosed it would have been quiet impossible to arrange marriage for a disabled woman like Anita.* Her parents became very anxious to get her married. After long search *her marriage was arranged in exchange of high dowry.* But the marriage did not last for long. Her greedy husband divorced her, as he did not get the promised dowry. Besides, during the two years of their married life the man was never able to accept Anita's disability. Anita dreamed of having a child out of the bond. But she had none.

**Everyone now neglects Anita. She gets sympathy from none. Anita is very depressed with the hazardous life she is passing. She is not able to mix with others just because she has hearing problem.**

She wants to hear as others, and also be heard; she wants to speak as others; she wants to be just like other non-disabled persons. She often questions herself as to why she is being punished in that manner. She sees this world to be very cruel and blames the so-called conscious people for her odds of life. At times she also blames God for all her pains and sufferings. She even wishes her death now to get rid of the sufferings she encounters.

Anita had the potentialities to be an active member of the family. In her teen-years she could perform many household activities. But she was never appreciated. Instead her family members would always blame and scorn her even for negligible fault she would have committed. Such harsh treatment severely affected her psychologically. She lost her self-confidence and all her potentials and capacities. Now she is virtually fully dependent on others.

But amidst this darkness she has been able to bring some light in her life. She has been able to earn some money by stitching. But whatever she earns she spent it for the family.

**Except from receiving some financial assistance no individual or organization has come forward for her rehabilitation. She has never been assessed of her hearing loss, not to speak of being given the hearing aids. She is living a life of disrespect, neglect, and discrimination. She has never had the opportunity to have the minimum level of her needs fulfilled. Rather every body had exploited her taking the advantage of her disability. Anita often sheds tears in pain and sorrow. She is able to comprehend life around her but she feels pain thinking that no one can understand the pains and sufferings that she has been experiencing through out her life.**

### Case study - 35

#### Love of a man has made Mabies life colourful

36 years old Mabia Begum lives in a village of Gaibandha district. Her husband is a businessman. But they are not very solvent. Mabia is visually impaired. She lost her eyesight as a result of an unfortunate and mysterious accident at the age of seven. One day while walking back home she hurt her eyes. But she could not realize how and what had hit her. After returning home she felt severe pain and burning sensation in her eyes. Mabia's parents took her to the village doctor. The doctor gave her some medicines to treat the wound. But it yielded no positive result rather the condition of her eyes deteriorated sharply. Water used to continuously drip from her eyes. She gradually began to lose her vision. One day, Mabia finally lost her eyesight.

Mabia's parents spent a lot of money for her treatment. But her condition had never

*...He had accepted Mabia for what she is. Mabia is now happy in her new family. After a few years Mabia became the mother of two lovely children. The children love their mother very much. Mabia is now a successful wife and a mother. However, it would not have been possible without the cooperation of a single man – her husband...*

improved. She was an unfortunate victim of wrong treatment by the village doctor. The parents of Mabia were illiterates. Mabia did not have the opportunity to study. She used to spend her days helping in the day-to-day activities of her parents at their home. Even though her parents cared and loved Mabia, her brothers and sisters showed negative feelings towards her. Her acceptance and status in the community was even worse. The neighbours used to tease and ridicule Mabia. They used to call her by bad names like 'Kani' (blind). No one wanted to mix with Mabia. They wanted to avoid her. For Mabia it was very disheartening and sad. She became isolated and led a life of loneliness.

Mabia's parents decided to arrange her marriage. They felt it would give her a place of her own and a man who would love and care for her. A businessman of that village came forward and married her. He had accepted Mabia for what she is. Mabia is now happy in her new family. After a few years Mabia became the mother of two lovely children. The children love their mother very much. Mabia is now a successful wife and a mother. However, this would not have been possible without the cooperation of a single man – her husband. *"... he is a great and kind man, with out him nothing would have been possible, I would probably have remain in the same condition in this cruel world if he had not married me,"* exclaimed Mabia.

Mabia had grown up in an environment that only provided barriers, but her life had transformed with a little cooperation. This cooperation and support gave her a new life, a life worth living.

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### Case study - 36

#### Tahmina still waiting for the Sunrise

Tahmina, 14, lives in the village of Masudpur in Gaibandha. Her father Taleb Ali is a day labourer. He is just managing to survive with his six members family. Tahmina has multiple



disabilities from her birth. Besides intellectual disability, Tahmina also has severe visual impairment.

Tahmina's mother had long labour pain during the delivery i.e. birth of Tahmina. Tahmina's father did not take adequate or appropriate measures during her mother's pregnancy and also at the time of birth. The family's poverty situation, ignorance and lack of medical facility are the major causes of not taking required steps by Tahmina's father during her birth. Moreover, Tahmina's birth took place in the hands of an untrained Traditional Birth Attendant (TBA). All these factors lead to the sad event of Tahmina being born as a disabled.

*...Members of the family have not been able to accept Tahmina. Her brothers and sisters cannot think of mixing with her. They don't consider taking Tahmina out of home to attend in any social events. They are even reluctant to eat with her...*

Although the limitations and problems of Tahmina were identified after her birth no treatment or rehabilitation services was arranged for her.

**Tahmina's family members were illiterate. Just as other members of the family she also had no scope to attain education. Besides, scopes and facilities were not available for people with multiple disabilities like Tahmina regarding their education and rehabilitation services in that community. Tahmina grew up amidst neglects and maltreatments. Members of the family did not accept Tahmina. Her brothers and sisters do not even mix with her. They don't consider taking Tahmina out of the home to attend in any social events. They are even reluctant to eat with her. As a matter of fact, she is kept in hide from the outsiders in such a manner as if she is an issue of great embarrassment and disgrace to the family.**

The neighbours and members of the community largely carry the wrong notion that they too could become disabled if they mix with Tahmina. Due to this belief they intentionally avoid the company of Tahmina. A few of the neighbours also ridicule her by calling odd names like 'Pagli' (mad), 'Kani' (blind). Such harsh treatment hurts Tahmina and fills her with sorrow, sadness, frustration and depression.

Tahmina has to be dependent on others for most of her daily activities. The members of the community blame her parents responsible for the situation, *'Tahmina has multiple disability as a symbol of divine punishment for all the crimes and sins that her parents had committed in the past'*, say many a one of the community.

Tahmina's parents are very worried about their daughter's future. There are very few organizations working for people with disabilities in that locality. Perhaps, this is the reason why no field worker or organization came forward to assist Tahmina to organize her life and proceed towards a better future.

Tahmina is now living in a world of darkness and helplessness. There are thousands more like Tahmina who shares the same fate like her. Perhaps, the time has finally arrived when we need to create a movement and change the dark world of Tahmina into a world of light and glaze opined the conscientious uses.

### Case study - 37

## Douloti: Life plunged into darkness for wrong treatment

Douloti, 45, was born in a poor family in Faridpur. She is the youngest among all her brothers and sisters. She was born normal and was developing and growing just like any other usual baby. When Douloti was seven years old, she had very high fever. As there was no M.B.B.S. doctor in the village, a local village doctor treated her. Unfortunately, Douloti was wrongly diagnosed and treated. As a result both her eyes became permanently and totally damaged. She lost her vision for good.

The environment within her family was always positive. The villagers considered that Douloti's present condition is the consequence of the crimes and sins committed by her parents. Being a disabled she has no acceptance in the society. She does not attend in any social activity. Douloti never got the opportunity to receive education. With the help of others Douloti manages to perform some of the household activities only.

*As there was no M.B.B.S. doctor in the village, a local village doctor treated her. Unfortunately, Douloti was wrongly diagnosed and treated. As a result both her eyes became permanently and totally damaged. She lost her vision for good*

Douloti gradually grew up and become an adult. Soon her family arranged marriage for her with a man named Abdus Sattar. He was a very good man and loved and cared for Douloti very much. Very soon, Douloti had three daughters. Abdus Sattar, Douloti and their three daughters lived with her father in a tiny house.

But Douloti's happiness did not last for long. Her husband died leaving her alone again with three daughters. With all her hardships Douloti was able to get her two elder daughters married. Now she begs with her youngest daughter for mere survival only.

At times Douloti blames herself for her odds. She used to love and care for her children to the best of her capacity. She had participated in many programs on disability issues being a member of a development organization. Currently, she is thinking getting her youngest daughter married. She is now in search of money for the marriage. *It is quite evident that her disability was not able to reduce the level of her responsibility.*

### Case study - 38

Chaireen's woes for the future!

Chaireen, 27, hails from a farmer family of Chuadanga district. Ever since the death of her father Chaireen started to live with her brother. Her brother, Maniruddin is also a farmer and heads a family of seven members.

At the very early days of Chaireen's childhood, her parents failed to realize that she might have any sort of problems. But as she grew up gradually they started to suspect that she was perhaps having difficulty in speech and hearing. By the age of eight months they became almost certain that their suspicion was true. Depressed, sad and confused the parents took Chaireen to a homeopathic doctor upon an advise of a neighbour. She was prescribed medicines. But no improvement was being recorded. Being further depressed and worried, the parents took Chaireen to another doctor who after some examination diagnosed that Chaireen had speech and hearing impairment. The parents were shocked and broken down mentally at the news and were thinking of the events of the future that await them and their daughter.

Nothing much was done for Chaireen in terms of providing hearing aid, especially due to prevailing poverty situation, grave in degree; of the family. But this had not stopped Chaireen in developing a mode or means of communication with her family members and others.

*...The world of Chaireen was limited with in the boundaries of her home. When she sees others speaking, gossiping, laughing, listening to music, Chaireen becomes depressed, it makes her disheartened, and she is filled with sorrow for being deprived of such basic human quality...*

Chaireen is well accepted within the family, especially for her sincerity and commitment in performing the household activities. From her very childhood Chaireen noticed that everybody were avoiding her including peers. She even felt her family members were keeping distance from her. Due to her disability her family did not take her to any social or community events. The world of Chaireen was limited within the boundaries of her home. When she sees others speaking, gossiping, laughing, listening to music, Chaireen becomes depressed, it makes her disheartened and she is filled with sorrow for being deprived of such basic human quality.

Chaireen never had the scope to study or to be trained on vocational skills. Illiteracy now forces her to live in a world of darkness. As she is unable to contribute financially to the family, she is not allowed to participate in family issues and decisions; her opinion has no value or importance to the family. She feels secluded and as a person of no value in this earth.

When Chaireen was a child, she used to move around the community by herself. But now as a grown up, she feels uncomfortable and insecure. With her age she feels her world is becoming further squeezed. Chaireen assumes that she will never get married. Others of her same age group are already married and have children. The day, she expects will never come, no one will come to marry her and share all her pains, sufferings, frustrations and depression. She will have to live a life in isolation as a burden in her brother's house. But what about the future, will she always be accepted in his family? She fears perhaps; the day will finally come when she will no longer have acceptance in this family too, especially as she has no income.

### **Case study - 39**

Seema: Symbol of self-confidence

Seema, 14, lives with her parents in a family of five members. Her father was the only earning member. His income was very low. Poverty had always been a regular companion to the family.

Seema was born with visual problems. She had no vision in one eye and with the other she could see slightly. The sizes of both her eyes were unequal. Her parents considered her impairments to be her fate.

Despite the limitations of Seema, her father did not differentiate her from his other daughters. She had been enrolled into school just like any other girls of her age. Seema is able to study due to the free education scheme offered by the Government for all female students. She beholds high expectation that she will be educated and build her career. But the free education scheme would end after her SSC and she knew that her father did not have the financial capacity to continue her education. Her parents are worried about the future of Seema too.

*...Even though the family attitudes were to some extent favourable, it was extremely negative in the community and also in the school, especially among the peers and the classmates. She was always teased and ridiculed by them. This hurt her a lot. A few of her friends pitied her but most neglected and stayed away...*

According to the socio-economic structure of the country the status of Seema's family was at the bottom. As an individual the condition of Seema is worse. In this male dominated society she suffers more for being a disabled and a female at the same time. Seema's growth from childhood to adolescent was not trouble-free. She had to face and overcome many barriers and obstacles in an unfriendly environment. Even though the family attitudes were to some extent favourable, it was extremely negative in the community and also in the school, especially among the peers and the classmates. She was always teased and ridiculed by them. This hurt her a lot. A few of her friends pitied her but most neglected and stayed away. Even though these were intolerable to her, she tried to overcome all these and socialize with people. *"... I know I am different from others, but is that a reason to treat me so harshly? It hurts me a lot and I become saddened when I am mistreated, but am I not created by Allah just like all other humans?"* asked Seema in a clam voice.

When Seema is alone she sinks deep into her thoughts, she despairs and becomes emotional. It gives her enormous sorrows when she thinks that her disability might be an obstacle to reach the future dreams. But she quickly conjures up all her mental strength and determination. She brushes aside negative thoughts. She fills herself with self-determination and vows to study and build up an excellent career. *"... I know I can do it, I only need scope and opportunity, I will conquer my disability with my merit, I will study and get a job and build a career, then perhaps I will get married and have a family"* said Seema.

Seema is undoubtedly a brave girl with strong personality. However, there are so much barriers that she needs to overcome in this world. But she is not a loser; she knows how to fight and how to win.

#### **Case study - 40**

Rehana paid heavily for independence of her motherland

Rehana Parveen is living with her elder brother. He is an engineer working in Dhaka. Rehana's father had died. She is the second among the three children of her parents.

**Rehana had severely fallen ill at the age of six months. The disease had softened and weakened her bones. As a result, she was walking in a crippling manner. Rehana's father had taken her to a doctor. The doctor had advised regular physiotherapy for Rehana. Then she was regularly taken to the Dhaka Medical College Hospital for physiotherapy. In the meantime, to get a cure, her father had resorted to religious, spiritual, herbal, and traditional healers. Gradually her condition improved slightly and she had started walking in a much normal manner. But at that time the War of Independence (in 1971) had started in the country. This however, did not stop her father from continuing with the physiotherapy. But as the condition of the country had worsened, it became virtually impossible for anyone to get out of the home, Rehana's father was also forced to stop going to the Dhaka Medical College Hospital for her physiotherapy.**

Rehana had no physiotherapy for the next seven months. The condition of her leg worsened steeply. Soon she was no longer able to walk. *The War of Liberation had brought freedom to the nation but at the same time, as many others, she too had to sacrifice* --- she had lost her ability of movement. Without appropriate care and service the situation of Rehana had worsened to such a state that she was no longer able to perform the essential activities of daily life on her own. She had to take assistance in eating, bathing, sitting and lying.

A few years back Rehana had developed an intense friendship with a man. Gradually their relationship had shaped from friendship to love. Everyone had presumed that the person would marry her. Rehana also dreamed of marrying this man and having a happy family. But the main intention of that man was exposed when he was proposed to marry Rehana. He demanded a flat as dowry. *Rehana realized that the man had not loved her he was rather interested in the wealth of her family.* Rehana had broken off the relation with the man. But even today she hopes that perhaps someday the guy would realize his fault and be back to marry Rehana.

All of the brothers of Rehana studied at different educational institutions. This had inspired and made her interested to study. Her father appreciating her interest appointed a private tutor to teach her at home. Rehana studied hard at home. This had also allowed her to spend some of her time effectively. *Despite all the love and care at home she is kept hidden by the family.* She is not taken to social events and if any guests come to their home she normally would have been kept inside her room. She had a few friends with whom she used to gossip over telephone.

*Rehana does not want to live a life of dependency and neglect. She wishes to go to her father. She waits for the time when it will finally arrive. Rehana lies in her bed and counts each of the seconds that pass and takes her closer to her death.*

At a certain stage of her life, Rehana had taken a job in a non-government organization. She used to teach children. But her brothers did not want Rehana to work. It was a trouble for them to take Rehana 'to and from' her office everyday. As Rehana had to depend on others for the journey to the office, she was often late. The employer was very dissatisfied. As a result, eventually she had to leave the job.

The most painful day in the life of Rehana is the day when her father died. She would like to visit and pray beside her father's grave but till today no one has taken her there. It is her lone

desire to visit her father's grave at least once before her death. But she waits anxiously as she fears that the day might never come. Among all the members of the family her father was her only friend. She used to have him beside her in every events and matters of her life.

Rehana's disability has not suppressed her mental faculties. She has composed about fifty poems. Some six of these poems have been published in different magazines. The subjects of all these poems are about her own sorrow, pains, sufferings, seclusion and about her father.

It is not possible for Rehana to participate in the family and social activities. This is mainly because no one provides time for Rehana. At times she really wants to go out but no one would give her company. It is only her mother who spends time with her. Rehana does not want to live a life of dependency and neglect. She wishes to go to her father. She waits for the time when it will finally arrive. *Rehana lies in her bed and counts each of the second that passes and takes her closer to her death.*

## Case study - 41

### Ignorance and ineffective treatment cost heavily on Dolayna's future

Mossamat Dolayna Khatun, 20, a woman with physical disability was born in Rajshahi. Both of her parents are day labourers. Her parents are in extreme financial insolvency and find it difficult to maintain the family of four members. Both her parents are illiterate. Besides, they have never shown any interest to educate their children.

*...With the passage of time Dolayna has grown up to an adult lady. Many of her same age group had already married and have children. Dolayna too wants a life partner, but her dreams still remain unfulfilled...*

At the age of five, Dolayna had high fever. But her parents sought no medical treatment for her. After a certain period, both her legs and her right hand became floppy. She could no longer stand and walk. Finally she was taken to a village doctor. He tried to treat Dolayna to the best of his capacity but could make no improvement. But as her condition was deteriorating with passage of time the parents of Dolayna moved to religious and traditional healers. But it was only wastage of money and time. Dolayna had polio, which the parents failed to realize.

Currently the physical condition of Dolayna is terrible. Both her two legs and one hand have been damaged extensively. As appropriate measures were not taken in the right time, two of her ankles, knees and the joints of her waist have become stiff. Even though Dolayna's parents would like to provide time and take care of her, they are unable, as both of them have to work hard all day out to earn money for maintaining the family. There is nothing that they can do except shedding tears in pains and sufferings. Dolayna could not meet with her peers as their parents had barred them from meeting with her. They consider Dolayna to be a symbolic representation of divine punishment for the crimes and sins that her parents had committed in the past.

Dolayna had passed her childhood and adolescence amidst a lot of barriers and sufferings. With the passage of time Dolayna has grown up to an adult lady. Many of her same age group had already married and have children. Dolayna too wants a life partner, but her dreams still remain unfulfilled. She is now psychologically depressed encountering the endless neglect and negative attitude of the society.

Dolayna is receiving some therapeutic treatment and other services under a local organization. But these services are inadequate to the extent of her needs. She is deprived of most of the human rights. If she had the scopes and opportunities to receive education, gain livelihood skills, have services for her disability, she too could perhaps establish herself and be contributive to her family, society and the nation like others.

**Case study - 42**  
Has Nazma a future?

Nazma, 13, was born in a very poor family in Faridpur district. She is the fourth among five children of her parents. During pregnancy period Nazma's mother was malnourished and could not properly take care of her fetus due to ignorance and poverty situation. Nazma's birth took place at the hands of an untrained traditional birth attendant (TBA). She got very limited care. Nazma apparently had normal physique. She was also seemingly growing up normally. But soon deviations were becoming visible. Her physical development also hampered. She was not developing according to her age. Gradually, visual related problems started to develop. Basically she had turned into a girl with multiple disabilities.

*...Most of the time she would remain irresponsible. Very occasionally it appeared as if she would like to play with other children, but all other children were afraid of mixing with her and did not accept her as she was much different in her appearance and behaviour...*

The problems of Nazma only deteriorated and turned more complex with time rolling on. Nazma was not also able to express her thoughts or feelings like sadness, happiness, anger, depression and etc. Most of the time she would remain irresponsible. Very occasionally it appeared as if she would like to play with other children, but all other children were afraid of mixing with her and did not accept her as she was much different in her appearance and behaviour.

Nazma has a lot of problems in movement, especially as she has visual impairment. She has to be dependent on others, primarily on her mother.

**At every step of her life Nazma is encountering difficulties due to her disability and social barriers. But due to the poverty situation and ignorance of her parents, therapeutic or rehabilitative services were not available to Nazma. Now her parents are caring and looking after her, but they worry about the future of Nazma, who would care for her?**

Actually who would care for many more boys and girls like Nazma? Do the society and especially the Government has not the responsibility to take care of the citizens like Nazma?



## Case study - 43

Munni: Name of a struggling lady

Munni, 25, is a woman with hearing impairment. She lives in Dhaka city with her parents. Her native village is in Iswardi, Pabna. Her father Jalil Mian is a retired senior bank officer. She is the fourth of her siblings. She had hearing problem since her birth. She couldn't talk even at the age of two. Her parent thought that their daughter would speak gradually, as one of her uncles developed delayed speech.

Time was passing but Munni couldn't talk. Her parents became worried and took her to a doctor for treatment in Iswardi. After examining Munni, the doctor informed that she couldn't talk because of hearing problem. But if she uses hearing aid she could hear sounds and gradually would be able to talk. As there was no special treatment and education facilities for the hearing impaired children like Munni in Iswardi, her parents came to Dhaka with her.

*...As a result of passing a lonely life at home, Munni started to show emotional problems. Her mother realized the situation and admitted her into class seven in a government school, situated at Mirpur. But Munni was again having inferiority complex...*

Munni was admitted into a hearing impaired school at Bijoy Nagar in Dhaka. One of her uncles sent a "pocket hearing aid" from Libya. But surprisingly the school authority suggested her not to use the hearing aid as they didn't know the benefit of using hearing aid. Her confused parent followed their suggestion.

Her parent appointed a house teacher of a hearing impaired school for teaching Munni. After one year her parents admitted her in HICARE, a special school for the children with hearing impairment. She was provided with an appropriate hearing aid from the school after assessing her hearing level. They also suggested her parents to teach her to speak.

After completion of primary level education from HICARE School her parents tried to admit her into a regular school. But from the beginning, her parents had to face a bitter experience. The principal of a regular school commented, "how could the parents of Munni even dare to think of admitting their disabled child into a regular school where non-disabled students have little chance to get admitted?" But it was hopeful that all people did not have the same negative attitude. Her parents got an opportunity to admit her into Class V of another school. But she was a little bit older than other students of her class. As a result, she couldn't interact and adjust with her classmates; she didn't get any help from or could play with them. As such she was passing a life without friends. She soon lost her interest in going to school. Eventually she stopped going to the school.

As a result of passing a lonely life at home, Munni started to show emotional problems. Her mother realized the situation and admitted her into Class VII in a government school at Mirpur. But Munni was again having inferiority complex. Her helpless and confused mother once again admitted her into a foreign funded special school. Munni built a good relationship with her class teacher. From her early childhood she had inclination in painting. Here she got the opportunity to practice painting. But it is a matter of regret that by depriving her the school authorities sold all of her paintings and earned a lot of money. When she came to know about this exploitation, she lost all her interest in painting and became frustrated. Gradually her

psychological and emotional problems intensified to such a stage that she had to stop her education. But her mother was not to be defeated. She continued with her efforts. She admitted Munni into German Technical Centre for training in embroidery. But again misfortunes followed her. She did well in written and practical exam but couldn't perform better in her viva as she was not able to understand the directions of the teacher. As a result, the authorities deprived her from getting a certificate.

But Munni couldn't give up her inner urge for painting despite all her deprivations. She received training in painting from a club. The club gave her some travel allowance. After completing her training, the club sold her paintings and earned money. However, they gave her forty percent out of the total earning. When a USA based organization working with children came to know about her painting they appointed her as a material developer in their organization. She became a favourite person of a high official of the organization. But after the departure of this official from the organization some of her colleagues blamed Munni without any valid causes. One of their blames was that she couldn't use the toilet appropriately. Munni still tried her best to keep at pace with her colleagues. But suddenly one day she was discharged without assigning any particular reason. They however mentioned that her position was no longer required in their organization. But after a few days they appointed a new person in that position who had no disability.

Now Munni has again become puzzled and emotionally upset. All of her talents are now meaningless. She has yet to know about her fault. Does it mean that all her talents are valueless to the society because of her hearing problem? Munni wants justice against all types of negligence and deprivation that has been forced upon her. She wants her job back and build up her future. But she doesn't know if rights of the people like her would ever be established.

## Case study - 44

Moushumi: Would she be able to face the cruel future?

**Mousumi Akhter, 10, is a girl with speech and hearing impairment. Mousumi is the eldest of two sisters. Her father is a service holder. They are a typical middle class family residing in Gaibandha.**

*...Mousumi had always fallen back in comparison to her classmates. But there was no limitation in the interest of Mousumi to continue with her studies. Her determination and the encouragement of her parents had always allowed Mousumi to attend school. Today just because she had continued with her studies, she is able to express herself in writing...*

Mousumi had no problem after her birth. At the age of seven months she had high fever. The fever had continued for long. As it did not subside, her parents took her to both the local homeopathic and allopathic doctors. But it was already too late and the damage took place. The treatment was able to bring the fever under control but her parents noticed that Mousumi was no longer responding to sound as before. As Mousumi grew up her parents also observed that her speech was not developing. Her parents became afraid and worried. They took her to the local health centre. After a few days of treatment, she was referred to Bogra Cantonment Hospital. She was treated there for twenty more days, but no improvement was recorded. *Ignorance and inappropriate or maltreatment had put Mousumi into a 'world of silence'*. By now her parents had spent more than thirty thousand Taka running after magical cure. Her parents have no botheration in spending the money but they feel sad that they were unable to find a cure for Mousumi. Through it pains them a lot at the situation of their daughter but they have not been able to deny the cruel reality that their daughter will not hear or speak properly.

The parents realizing the feelings of their daughter have always tried to protect her from being mentally upset. Her father had enrolled her into a regular school when she was of school going age. As she had speech and hearing impairment and the teachers were not skilled in teaching children like her, Mousumi had always fallen back in comparison to her classmates. But there was no limitation in the interest of Mousumi to continue her studies. Her determination and the encouragement of the parents had always imbued Mousumi to attend school. As she had continued her studies, she is now able to express herself in writing.

Mousumi often plays with her friends. But as she is not always able to communicate with them she gets frustrated and angry sometimes. This limitation of not being able to communicate pains her immensely, but there is none around her who can comprehend her sufferings.

Mousumi's parents are very much worried about her future. *They are uncertain and anxious as to how far Mousumi would be able to progress with her education, will she ever get married; who will look after her in the future?* Mousumi had not yet faced all the cruel realities of this harsh world. But soon she will have to encounter all the challenges that are waiting in her life. Her parents pray that Mousumi grows up to have the courage and strength to face obstacles of the future and is able to build a beautiful life for herself.

## Case study - 45

Abhi : Disability defeated!

**Dhuti Shanchita Abhi, 16, of Rangpur is a very famous national tennis player. She is a hearing-impaired by birth. Her father is a government service holder and her mother is a teacher of a special school.**

In the early days after her birth, her parents could not realize that their daughter had difficulties in hearing. They had presumed, "... perhaps some dirt had accumulated inside her ear which limited her hearing." As Abhi was growing up she was not responding to sound or developing her communication skills like others of her age group. When she was of eighteen months old, she was taken to the Rangpur Medical College Hospital. In the hospital, the ENT specialist examined Abhi and identified her to be a Speech and Hearing Impaired. The doctor also advised Abhi's parents to admit her to a school for the speech and hearing impaired in Dhaka when she is 6 to 7 years of age. He also advised that she would be able to study in a special set-up.

Abhi's parents were beleaguered at the situation of their daughter. They immediately rushed to Dhaka and consulted with a famous ENT specialist. Abhi was examined again and was

*...Abhi is continuing her education alongside her extracurricular activities. She is sitting for her S.S.C examination this year. She wants to be a computer scientist in the future. Today Abhi is an example for all people with disabilities. Her parents endeavours and her own efforts have made her life successful...*

identified as severely hearing impaired. But the doctor was not too pessimistic, "... she would learn to talk with the right hearing aid and speech therapy," opined the doctor. Abhi's parents took her to HI-Care school in Dhaka to measure her hearing loss properly and get a hearing aid. They also availed of the scope and enrolled her into the school. They left Rangpur and settled in Dhaka to ensure required facilities for their beloved daughter.

Abhi progressed impressively in the school. The parents and the teachers of the school tried with all their efforts to develop the language ability of Abhi. Her mother also developed her skill on the ways and means of teaching and facilitating language development of Abhi. Soon Abhi was able to master the skill in using language for communicating with others.

After studying for four years in the special school, she was enrolled by her parents into a 'regular' school. This was a start of a new era of her life. As it was not visible, the regular schoolteachers had not initially realized that she was hearing impaired or that she was having problems in studying. They also felt no necessity to take special care. But at home her mother always provided special attention and care for Abhi and her studies. Abhi's mother had also enrolled her into Sishu Academy to learn Painting and also admitted her in a dance school. Besides, she was also admitted in the National Tennis Complex to learn how to play tennis. From the very childhood Abhi has been participating in many cultural events. She won many prizes in such events competing with the other non-disabled children.

Abhi has keen interest for playing tennis. Sincere determination coupled with hard work has brought her fame and popularity in tennis. She participated in many international competitions and earned recognition and prizes. She is the first Bangladeshi girl to attain the 127<sup>th</sup> position in the ITF junior world ranking. Abhi is continuing her education alongside her extracurricular activities. She is sitting for her SSC examination this year (2000). She wants to be a computer scientist in the future. Today Abhi is an example for all people with disabilities. Her parents endeavours and her own efforts have made her life successful. Her disability has been defeated to her geniuses.

**Determination helped Momtaz to overcome disability**

Momtaz is married and lives in Faridpur with her husband and son. She is a woman with visual impairment. When Momtaz was seven years old, she had very high fever. The fever carried on for long time. Her parents took her to traditional and herbal healers. The fever had finally subsided. But her mother noticed that Momtaz had difficulty in walking. One day Momtaz was not able to find a plate that was in front of her. Her mother became very afraid observing her condition. The neighbours started to pass various comments and became suspicious about Momtaz. Some even thought that the evil spirits had behold upon her. A village doctor was called to examine Momtaz. He assessed her condition and advised her parents to take her to an eye specialist.

Her parents took Momtaz to an eye specialist. The doctor examined her and provided some medicine stating that no operation would be required now. But as days had rolled on Momtaz's visual acuity deteriorated. Gradually a white layer formed over the right eyeball. Momotaz also started to feel pain causing burning sensation on her left eye. She was taken to an eye campaign where an operation was performed on her left eye. She was also advised to wear black spectacles. But all these had no effect. Soon she lost her vision of the left eye. Gradually, she also lost vision of the right eye. She is now a totally visual impaired person.

*...She was very intelligent. By listening to others she has been able to learn the Quranic verses needed to say the prayers. But there was no other opportunity available to her to receive any other form of education, mainly due to the ignorance and neglect of her family...*

Momtaz's problems only increased after her blindness. The members of the family were not treating her well. They started neglecting and avoiding her. She had no friends and the relatives always kept her at bay. It was as if her crime to be a disabled. Nobody loved or cared for her. She felt isolated, alienated and secluded. Momtaz also did not attend any social or family events. Gradually, she has developed a kind of hatred on herself.

From her very childhood Momtaz was keenly interested in studies. She was very intelligent. By listening to others she has been able to learn Al-Quaranic verses needed to say the prayers though she was a girl with visual impairment. But there was no other opportunity available to her to receive any other form of education, mainly due to the ignorance and neglect of her family and the community.

With time rolling on Momtaz grew up to be a beautiful lady. Her father wanted to get her daughter married and have the son-in-law stay with them. But Momtaz did not agree to it as this will downgrade her socially, moreover, the would-be the husband may be keen on receiving dowry. But her father did not pay any heed to her opinion, found an apparently suitable man and married his daughter off. She started a happy married life initially. After one year they were also blessed with a beautiful child. But her happiness did not last long. As she had feared initially, her husband left her and married for the second time.

However, Momtaz was not totally broken. She started the struggle afresh to be independent. Her son was a source of great inspiration. Momtaz tried her best to rear her son. A local development organization had identified Momtaz and offered her different vocational skills to provide scopes of income generation. She was also funded with BDT 5,000 as loan. With the money Momtaz raised some poultry and goats. She contributes part of her income to the family expenses. In addition to, contributing to the family expenses, Momtaz had even bought a milking cow with the savings that she was able to make.

Now Momtaz is self-dependent. She no longer considers herself as hopeless. She has her own poultry farm. The cows and goats are on hire. Momtaz is now spending happy times; she has also been able to make some savings. Disability was overcome by the determination of Momtaz.

### **Case study - 47**

Taposhi: Isolation, the way of life

**Taposhi, 12, lives in the village of Adimpara of Gaibandha district. Her father, Huda is a small businessman. They are extremely poor with a seven-member family. Taposhi is a girl with intellectual disability since her birth. Her mother had long and painful labor during her birth.**

*...Taposhi's parents are still in absolute darkness and ignorant of what can be done to improve the condition of their daughter. They have accepted Taposhi's condition as fate. Without proper interventions and guidance the condition of Taposhi is not only worsening but she has become dependent on others for almost all activities of daily living...*

Taposhi's parents could not identify or assess that she had any problem. To her parents, she was growing and developing just like any other non-disabled children. But a few months after her birth, it was evident that Taposhi was not behaving appropriately to her age. A few days passed but no positive change in her condition was seen. Her parents became anxious and worried. They took her to a doctor. Taposhi was examined by the doctor and told that she would recover, as she would grow older. Her parents were relieved at the hope that was relayed to them. But little did they knew that the hope that was given by the inexperienced doctor was false. Since visiting the doctor they had neither consulted with any other doctor nor taken any other interventions to help their daughter. The parents waited patiently expecting their daughter to recover. But disheartening the parents, no better development occurred to Taposhi as time rolled on. The wrong advise of the doctor had ruined the life of Taposhi. The parents were ignorant and also not informed about appropriate interventions for Taposhi. They had not sought any rehabilitation support that could have really helped their daughter.

Currently, Taposhi has many problems. Taposhi's behaviour is now maladaptive and much worse than before. The condition is unfortunate but it is because of lack of appropriate interventions to improve her behaviour. She cannot talk or communicate properly. She can only communicate with sign when she is hungry or needs to go to toilet. She gets excited quickly and is very stubborn. The family members of Taposhi are in a very embarrassing situation in the community.

Taposhi's parents are still in absolute darkness and ignorant to what can be done to improve the condition of their daughter. They have accepted Taposhi's condition as fate. Without proper interventions and guidance the condition of Taposhi is not only worsening but she has become dependent on others for almost all activities of daily living.

Even though other children are getting education, Taposhi's parents had never thought of enrolling their daughter into any school. Even if they wanted, there is no scope for education in the locality for children like Taposhi. She has never been well accepted in the family. She is considered only as a burden to the family. Similarly, she has very limited acceptance in the community. *Taposhi had always been detested, neglected and disliked by the community. Taposhi was ill treated and avoided. No one wanted to mix or communicate with Taposhi. She was a source of fun and mockery among her peers. Taposhi was deprived of all opportunities of socialization. Every day for Taposhi is a day in seclusion and isolation.* Her parents at times worry about her future. They wonder who will look after her after their death.

### **Case study - 48**

Love, not religion mattered most to Maloti, now Kamrunahar

**Maloti Rani, 20, is a woman with visual impairment. She was born in a poor Hindu family of Chuadanga district. In course of events of life Maloti had married a man named Abdus Samad – a Muslim by religion. He is also a person with visual impairment and works as a newspaper hawker in Chuadanga. As her husband was a Muslim, she converted also to Islamic faith to marry the man of her choice and has taken the Muslim name Mossammat Kamrunahar. She now lives with her husband in a small hut. This couple – both with visual impairment and a different religion before – has been blessed with a son.**

**Kamrunahar was not born with visual impairment. When she was two years old she started to have problems in her eyes. Tears used to be continuously discharged from both of her eyes. Her parents became worried and confused at that time and did not know what to do. Most of the community members opined, *'It must be the winds of the evil spirits'*. According to the advice of the neighbours, the parents took her to a religious healer. She was provided with 'Special or holy Water' for regular application into the eyes. They applied it regularly but instead of improvement further damage occurred.**

*...Kamrunahar, previously Maloti Rani took Islam and changed her name. The family of Kamrunahar extended their full support and created no barrier, though she was changing her religion. They never thought Kamrunahar would ever get married...*

**With time passing on the condition of Kamrunahar's eyes deteriorated. The parents were further confused and puzzled. At this stage, a neighbour advised them to smash a bark of a certain tree and apply the discharged liquid into her eyes. But as soon as this was done, pain and burning sensation enhanced immensely and she quickly lost her vision. *The life of Kamrunahar was now without light, a life that could perhaps been avoided only if her parents and the community were not so ignorant and***

*superstitious on issues related to eye health.* She now hopes that no one else would become victimized like her due to lack of awareness and wrong treatment.

The parents of Kamrunnahar (Maluti) always felt guilty of their ignorant acts causing blindness to their daughter. The sad events of the past had shaken them severely. They decided to seek advanced treatment as advised by a few local elites. They collected money with much difficulty and went to Kolkata for Maloti's treatment, but it was already too late. Damage to her eyes had become permanent. The doctors told them she would never get better or regain her eyesight.

Maloti accepted her impairment. However, she prepared herself mentally to face the reality and fight it back. The parents observing the keen interest of their daughter in studying enrolled her into the integrated school for the visually impaired in Chuadanga. She studied there and passed SSC successfully, overcoming many barriers and challenges. Her impairment was not able to depress her or affect her mental strength. She was also able to effectively establish her position within the family and the community.

At such a stage, Maloti met Abdus Samad. They immediately developed likings to each other, which turned into an affair and finally they decided to marry and live their life in union. Kamrunnahar, previously Maloti Rani took Islam and changed her name. The family of Kamrunnahar extended their full support and created no barrier, though she was changing her religion, they never thought Kamrunnahar would ever get married.

Kamrunnahar is happy in her personal life. But it is not the same in her professional life. After completing SSC, she did not have any scope to continue her studies or get a job. She often wails that due to lack of opportunity whatever efforts and resources had been put behind her studies became an almost complete waste. These thoughts often depress Kamrunnahar. But this did not stop her in progressing in life. With the help of her family members she is managing her business – a small shop. This has allowed her to contribute to the family income. The family and the community appreciate and respect her determination and value her opinion. She is no longer depressed. She is leading a happy life with her husband and son. Now her only dream and aim in life is to see her son educated and well established in the coming days.

#### **Case study - 49**

Self - independence, not marriage is more valuable to Sheully

Sheully lives with her parents in Jhenaidah. Her father is an owner of a small shop. He maintains his family of six members out of its income. So, poverty has always been a feature to the family.

Sheully is a girl with profound speech and hearing-impairment. At the fifth month of pregnancy, Sheully's mother had very high fever for seven days. At this stage the doctor had prescribed high power medicine and injection. After a few years of Sheully's birth, her parents became worried, as she was not able to speak. They took her to a traditional healer for treatment. But as no improvement was seen they gradually accepted that Sheully is a speech and hearing-impaired girl.

*... Sheully has another friend who is also a girl with profound speech and hearing impairment. They meet each other almost every day and express their feelings / mind to each other. They at times wonder that they both being disabled are able to communicate with each other but why not with the others...*



Sheully is now 12. She never had the scope for education. Even though Sheully had a lot of interest in receiving education, but due to negative attitude and feeling of the local school teachers she was not enrolled into the school. The teachers had commented, '*A hearing-impaired girl like Sheully would not be able to learn. Besides, she would hamper other students' learning*'.

Recovering from this sad experience, the parents of Sheully managed to enroll her into a non-formal school run by a local NGO. She studied there for the maximum duration of eighteen months. Now she is undertaking sewing training. Sheully is very eager to obtain newer skills.

After completion of non-formal education, Sheully's parents and relatives were amazed to see the knowledge that she had gathered. They thought Sheully would not be able to learn much. A rehabilitation worker of a local NGO helped Sheully to develop a communication board. With the help of this board and through her gestures she is now able to express a lot of her essential needs and feelings.

Many of the peer students used to ridicule and call Sheully by bad names in the absence of the teachers. Although she did not hear what they were saying yet she could understand that she was being ridiculed. This used to fill her heart with sorrow and pain. She often went to the riverside alone and shed tears in silence. However, there were two children of her age who came forward as friends and tried to understand her, give her time and help her in many ways. Sheully has another friend who is also a girl with profound speech and hearing impairment. They meet each other almost every day and express their feelings/mind to each other. They at times wonder that they both being disabled are able to communicate with each other but why not with the others.

Sheully regularly attends social events. She mixes with all, regardless whether she is accepted or not. *Sheully believes her rights have to be established by herself, no one else can or will do it for her.*

Sheully is very beautiful. As such her family receives a lot of proposals for her marriage. But Sheully has learnt from life that any person who has no education or is not established has little value in the society. The condition of a disabled person would be much worse. As such Sheully had decided that she would never get married until she is educated and possesses essential skills to be able to lead an independent life.

### **Case study - 50**

Ruposi leads a life in silence

Ruposi is the youngest in a family of four sisters. Her father, Md. Abdul Barek is a service holder. Ruposi lives with her parents in a village of Chuadanga district. Her parents could not recognize at the beginning that she had hearing impairment. But as Rupashi grew up and was not able to communicate with others, her parents could realize the problem. Her parents were anxious and worried at the condition of their daughter. After consulting with their neighbours they had taken Ruposi to a village doctor. The village doctor had, however, rightly identified her as a speech and hearing impaired girl. The parents sought different treatment for Ruposi but no improvement took place.

The parents of Ruposhi were so much conscious that they did not want to deprive their daughter from acquiring education. She was enrolled into the nearby school at the appropriate age. Currently she is studying in Class IV at Akanda Baria Government Primary School. Though she has the opportunity to study, but peers and others at the school often do not like to mix with her. Nobody understands or tries to comprehend her expressions. Such lack of communicative skill has limited her world. She has to remain dependent on others for many reasons.

*Ruposi does not have positive views about marriage. She thinks she will never be able to marry like others as she has a disability. Even if she is married, her conjugal life may not be happy because of the fact that the family members would not be able to communicate with her*

Due to lack of acceptance she does not get opportunity to participate in social activities. But the encouraging fact is that the members of her own family warmly accepted her. Ruposi is really loved and cared by her parents and sisters. Despite the love and care, she has no access in decision making on any affairs of the family. This discrimination often hurts Ruposi and fills her with sorrow. She considers, it doesn't matter how much education she gets or involves herself in income generating activities, her rights as a human being will never be established just because of her disability. Ruposi does not have positive views about marriage. She thinks she will never be able to marry like others as she has a disability. Even if she is married, her conjugal life may not be happy because of the fact that the family members would not be able to communicate with her. This might create misunderstanding and problems for her. As such she fears that perhaps she will forever have to live a life of dependency. She is afraid that she will remain a burden to her parents and sisters.

At times Ruposi blames her parents for her disability. Perhaps, she is a symbol of the sins that her parents had committed. When she is depressed she sheds tears in pain and sorrow for being disabled. *She wonders if there were nothing that could have been done to fill her silent world with sound.*

# Recommendations

- The issue of inclusion of women with disability in job place should be considered as rights. The development organizations both government and non-government involved in job creation and skill development should consider the women with disability as priority target beneficiaries.
- The organizations involved in providing skill training to community people should develop specific areas of skills development suitable for the disabled persons specially the women with disabilities.
- Organizations concerned with mass education on various development issues should initiate general sensitization programme to create a favorable working environment for person with disabilities, particularly the women.
- Referring to the national building code, persuasion should be made with the concerned authorities by the networking organizations working with disability issues for creation of accessibility provision for the persons with disability in public and job places.
- In line with themes of the national policy on disability, special need based facilities for the people with disabilities in workplace should be established through persuasion with concerned authorities. The development organizations working with disability and the self-help group of people with disabilities should initiate systematic intervention and campaign for such persuasion.
- The prevailing understanding and beliefs at community level on causes and treatment of disability are absolutely negative and wrong in most cases. Superstition still exists in most communities, which seems to be the main barrier for the development of people with disabilities as a whole. This has to be addressed by the development activists to create a positive understanding through mass communication and counseling.
- The health centres at least at district level should have facilities of primary health rehabilitation services like physiotherapy, occupational therapy, orthopedic services etc. to attend persons with disabilities. And the girls and women should get extra care. Provision for screening and referral services should be initiated in primary health care services at community level.
- The concept of inclusive education should gradually be initiated in all mainstream education. This requires systematic inclusion of inclusive education concept in national education curriculum. Disability orientation needs to be included in teachers training curriculum in both formal and non-formal education.
- Development organizations concerning education should take initiative to motivate local education authorities for inclusion of girls and women with disabilities in regular education programs.
- Access to the educational institutions for the disabled learners, with girl preference, should be ensured. The planners of educational infrastructures could play a significant role to create accessibility in public educational institutes.
- Provision of allowances for disabled children especially the girls would encourage for their inclusion in education.

- Facilitation should be made to the development organizations working at community level to initiate counseling and awareness raising program for attitudinal change of community people on disability issue.
- Organizations concerned with the women rights and justice can be sensitized to pay more attention to the vulnerable situation relating to the marriage of disabled women. General sensitization can be made to create opportunities of access to the family court of disabled women.
- Development organizations should take active role to provide legal aid-support to the victims of failed marriages particularly to the women with disability.
- Social services and development programs could initiate guidance and counseling services for the girls and women with disabilities and their parents to increase their self-confidence and adaptation with environment and reality.
- Organizations both government and non-government working with health issues should provide required education and training for health workers and traditional birth attendants so that they can facilitate the girls and women with disabilities to manage reproductive health properly.
- Reproductive health education is required to be included in common curriculum of mainstream education to create awareness and impart knowledge on reproductive health. This will ultimately help reducing the vulnerability of girls and women with disabilities particularly to special feminine need.
- Community sensitization campaign on abuse of girls and women with disabilities could be systematically integrated in general sensitization programme. The development agencies and local government authorities should extend legal aid support to the victims of such abuses, if any.
- Help lines Telephone communication can be initiated with the collaboration of security services for immediate information and support to the girls or women with disabilities in case of abuses and unwanted incidents in urban areas.

## References

- *Bangladesh National Gender Profile*, (1999) UNDP Bangladesh.
- Esther Boylan (1991), *Women and Disability*, Zed Books Ltd: London.
- Lina Abu-Habib (1997), *Gender and Disability*, Oxfam Publication.
- Rahnuma, Afrin (2000), *Adolescence Trapped Motherhood Image*, ActionAid Bangladesh.
- Sarah C White (1992), *Arguing with the Crocodile: Gender and Class in Bangladesh*.
- Susan Lonsdale (1990), *Women and Disability*, Macmillian Education Ltd.
- CSID (1999), *Unveiling Darkness*, Centre for Services and Information on Disability (CSID): Dhaka.

- CSID (1999), *Street Children with Disabilities*, Centre for Services and Information on Disability (CSID): Dhaka.
- Khan, Shalma et al (ed.) (1981), *Inventory for women's organizations in Bangladesh*, UNICEF Bangladesh.
- National Policy on Disability (1995), Bangladesh.
- Bangladesh Five Year Plan (1997-2002).