

## BRIEF REPORTS

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# Financial Aid for the Rehabilitation of Individuals with Spinal Cord Injuries in Bangladesh

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### ABSTRACT

*In Bangladesh, a majority of individuals with spinal cord injuries (SCI) are either poor or very poor. In most cases, their families undergo extreme hardship as they lose the income of the only or main earning member, and are unable to bear costs of rehabilitation.*

**Purpose:** *This mixed method study explored perspectives of individuals with SCI regarding financial aid in the form of interest-free loans for their treatment and rehabilitation at the Centre for the Rehabilitation of the Paralysed (CRP).*

**Method:** *In the first part of the study, 10 semi-structured face-to-face interviews were conducted. In the second part of the study, 40 persons with SCI were surveyed. The qualitative method involved selection of respondents according to their age, sex and severity of disability. Quantitative interviews were conducted with all persons with SCI in the final stage of hospital rehabilitation, in the third quarter of 2008.*

**Results:** *Though CRP provides financial support depending on the individual's economic status, many persons with SCI needed additional funding from multiple sources, such as savings (42.5%), mortgaging assets (12.5%), selling assets (45%), receiving loans (37.5%), begging for money (42.5%), and receiving donations from relatives (47.5%) or the community (30%), to meet the direct and indirect costs of rehabilitation. Majority (85%) of those interviewed wanted to receive financial aid in the form of interest-free loans. 76.4% of them wanted the loans to be disbursed in two phases; initially, to offset some of their costs during rehabilitation at CRP, and thereafter, for economic*

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*reintegration in their community. The remaining 23.6% wanted the loan only for vocational reintegration. 70.59% of those interviewed proposed repayment in monthly instalments, while 17.64% suggested quarterly instalments and 11.76% favoured annual instalments. Over half of the participants (55.88%) wanted to have vocational training, and the rest wanted vocational training for their family members, to enable them to repay the loan.*

**Conclusions:** *This study revealed that there is a huge demand for interest-free loans among people with SCI. An appropriately designed interest-free loan programme, which would be sensitive to individual needs, could save people with SCI and their families from bankruptcy. This would also make SCI rehabilitation programmes more sustainable, and possibly reduce over-dependence on the donors. Further action research is recommended to evaluate the effectiveness of such a course of action.*

**Key words:** *Vocational training, Spinal cord injury, Interest-free loan, Financial aid.*

## INTRODUCTION

Traditional beliefs, prejudices and negative attitudes towards people with disabilities are predominant in Bangladesh (Momin, 1995). Negative attitudes and practices reinforced by poverty create barriers that exclude people with disabilities from mainstream development activities and employment opportunities (Khan et al, 2002). Disability and poverty are closely related; one can be the cause or consequence of the other (DFID, 2000). Impact Foundation Bangladesh (2002) reported that 14% of the functionally landless people (owning 0-1 acre of land) are persons with disabilities. Bangladesh is a densely populated developing country, where 49.8% of the people are living below the national poverty line (UNDP, 2007). Over the years, surveys have shown varying estimates regarding the prevalence of people with disabilities in Bangladesh, ranging from 0.5% to 14.04% (Handicap International Bangladesh and NFOWD, 2005). The absolute annual growth rate of population with disability in Bangladesh is reported to be approximately 250,000 (Impact Foundation Bangladesh, 2002).

Centre for the Rehabilitation of the Paralysed (CRP) was founded in 1979, in response to the urgent need for services for people with spinal cord injury (SCI) in Bangladesh. Currently, in addition to many other services for people

with disabilities, CRP runs a 100-bed hospital for persons with SCI and follows a holistic approach to rehabilitation. Physical rehabilitation is provided through medical and therapeutic interventions and the provision of appropriate mobility aids. Psychological rehabilitation involves counselling and sharing of experiences; and economic rehabilitation is provided through vocational re-training and assistance in securing micro-credit loans. CRP's work is financed by four main sources: donations from overseas or Dhaka-based representatives of foreign agencies, donations from local sources, income from commercial projects and contributions from services users (CRP, 2011). About 75% of CRP service users are from poor economic backgrounds (Momin et al, 2001). Many of them cannot pay the full cost of the services.

Participation in economic activities is important not only to earn a living, but also to experience self-fulfilment. Work offers people with disabilities the opportunity to be recognised as contributing members of their family and community, and thus enhances their self-esteem. In developing countries these people usually turn to self-employment because of lack of opportunities in the job market. Although many would prefer to have a job with a regular income, self-employment is often the only option available. To be successful, self-employed people need, among other things, access to financial services, in particular micro-credit (de Klerk, 2008).

As a part of CRP's integrated approach, the CRP micro-credit programme for poor people with disabilities was established in July 1999, at Savar, Dhaka. The objectives of the scheme were to help these people to build up small businesses through self-development activities, to integrate them into the community development activities, and to promote equal opportunities for them within the community. The programme was completed in June 2003. In the course of the project, CRP disbursed Tk. 4290500.00 (52412.66 USD) among 573 persons as interest-free loans. Among the recipients, 302 were people with disabilities, 212 were family members of people with disabilities, and 59 were poor people without disabilities. The loan return rate of this programme was 99% (CRP Social Welfare Department, 2008).

Recently, the adoption of this programme was under consideration for people receiving treatment and rehabilitation services from CRP. With CRP's regular support, this interest-free loan facility is also expected to aid in the economic reintegration of people with disabilities, thus saving them from bankruptcy. Before starting such an ambitious venture, it is important to know how these

people would repay the loan and how they could be helped to pay the instalments. Hence, this study was undertaken to understand how people with SCI manage their funds during treatment and rehabilitation, to find out the challenges faced by them and their family members, to understand whether they need interest-free loans, to explore the loan repayment options, and to understand the type of help they expect from the loan provider for easy repayment of the proposed interest-free loans.

## **METHOD**

A mixed method research design was used. Qualitative methods were used to gain insights into people's views, opinions, feelings and beliefs, whereas quantitative methods were used for measuring and counting those views and facts through descriptive analysis of data (Hicks, 1999). In the first part of the study, 10 semi-structured face-to-face interviews were conducted. In the second part of the study, 40 persons with SCI were surveyed. Respondents for the qualitative study were selected purposively considering their age, sex and severity of disability, while for quantitative interviews all people with spinal cord injury who were at the final stage of their hospital rehabilitation in the third quarter of 2008, were approached. All interviews were conducted at CRP.

Verbal informed consent was obtained from all participants. The purpose of the study was explained and confidentiality of the information provided was assured. Participation was voluntary and they were informed about their right to withdraw at any time. Ethical permission was obtained from the CRP Ethical Review Committee.

Qualitative interview transcripts were read several times to understand the inner meaning of the data and what the participants actually wanted to say. The data were then organised according to the interview questions, and the major categories were formulated from the transcripts. Using content analysis technique, the different codes were placed under these major categories. Content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding (Steve, 2001). Separate codes were used to make sure that the entire course would not be the same. If any appeared similar, they were merged into the same code. Finally, the codes were tabulated. The quantitative data were analysed using simple descriptive statistics.

## RESULTS

### Respondents' Background

Participants were between 12 and 60 years of age. The mean age was 34.34 years, median was 35 years and mode was 40 years. Majority of the respondents (74%) were married. The male-female ratio was 9:1. More than half of the respondents did not have any formal education. Respondents' educational qualifications are presented in Figure 1. Analysis of the respondents' pre-injury occupations revealed that most of them were involved in occupations which require heavy physical labour and manual handling (Figure 2).

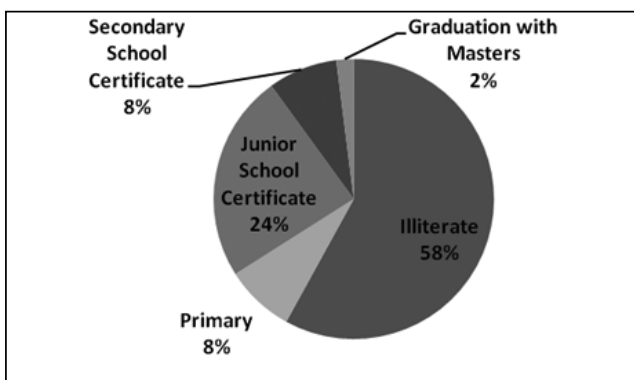


Figure 1: Educational qualification of the respondents

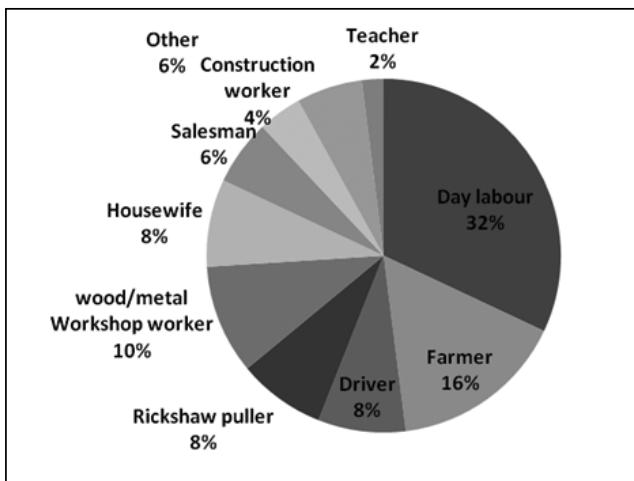


Figure 2: Pre-injury occupations of the respondents

## Managing Money for Treatment and Rehabilitation

In addition to CRP's regular financial support, 42.5% had to resort to begging, 45% had to sell assets, 37.5% received loans from informal sectors at high interest rates, 47.5% received donations from relatives, 30% received donations from their community, 12.5% had to mortgage assets, and 42.5% used their personal savings to offset some of the direct and indirect treatment and rehabilitation costs.

Mr. Jamir, a 40-year-old person with paraplegia who used to work as a day labourer in a rural village of Bangladesh said, *"I am receiving treatment at CRP for the last three months. I do not know the total amount of money already spent, but personally I had to spend 15000.00 taka (USD 183.43). Among this amount, my savings was 3000.00 taka (USD 36.69) and my sister could contribute only 200.00 taka (USD 2.45) because her financial situation is not also good. In this circumstances, my wife and I rented a van to knock people's doors in my and neighbouring villages to beg the rest of the money (11800.00 taka or USD 144.30). It took us three months to collect this amount. In my life I never begged, it was the first time I had to beg because I did not have any other alternatives. People did not behave badly with us and they gave whatever they could, but it was very disgraceful."*

Another participant Mrs. Rahima, a 30-year-old rural housewife, revealed, *"I had to sell my house to continue my treatment, now my children are staying with my mother. My children have lost their shelter. My mother is also very poor. She is struggling to feed my children. Now, they have no alternative but begging."*

As a consequence of SCI and spending money for treatment and rehabilitation, almost three-quarter (70%) of the respondents mentioned that they were having difficulty in feeding their family members, 7.5% said their family members had become homeless, 10% revealed that their family members had resorted to begging and had to stop schooling of their children. Qualitative interviews found that because of their lowered social status, persons with SCI and their family members suffered loss of dignity.

Mr. Karim, a 42-year-old farmer who is a paraplegic, said, *"There are 12 people in my family, but only my elder son and I used to earn money to support my family. Now only my elder son is earning for our family, but his income alone is not enough to run our family. Day by day the price of foods is increasing, for this reason most of the time my family members cannot eat properly. On the other hand, after completing my rehabilitation, when I return home I will have to repay the loan that was borrowed. But, I do not have any idea how I will repay it. I do not have any more assets or land*

*property to sell. Because of this financial problem, my two children had to stop going to school."*

Mr. Salam, a 35-year-old rural rickshaw-van driver who became paraplegic because of his SCI, said, *"On admission at CRP I deposited 6000.00 taka (USD 73.37) as my treatment cost. I have collected this amount by mortgaging my 10 decimals land to my elder brother. I will get back my land only after I repay the loan. I was the only earning member in my family. Two of my children are now living with my parents and my wife and my youngest child had gone to my father-in-law's home because my parents are unable to feed all of them."*

Mr. Rahmat, a 27-year-old tetraplegic person who used to work as a day labourer in a port, said, *"I was the only bread-earner of my family. My siblings collected donation from the community to bring me at CRP. Now my mother and sister are working as maid-servant. They never did this job before my injury."*

### **Need for Financial Aid and Options for Repayment**

Majority of the respondents (85%) wished to receive an interest-free loan and were confident of repaying it, with certain conditions. The other respondents (15%) did not want any kind of loan. It was found that respondents wanted the interest-free loan to offset some of their hospital rehabilitation costs, and thereafter to start small businesses for economic integration, and to modify their homes for increased accessibility. They also wished to involve their family members in their businesses because often it was not possible to function independently, due to their impairments and environmental barriers.

In this regard, Mr. Hossain said, *"In addition of my treatment costs, I would love to have a loan of 20,000.00 taka (USD 244.57). Initially I would invest 10 thousand taka (USD 122.29) to rent some land from my neighbours. My father and brother would grow crops or vegetables in that land. I would like to spend the remaining 10 thousand taka (USD 122.29) to set up a mobile phone service centre (a shop where people would have to pay money to make calls) and the money that I would be able to earn from this service would be enough for paying the instalments. So, I think it won't be impossible for me to repay the loan."*

Another participant, Mrs. Khadija who was a school teacher, mentioned, *"My husband had to loan a lot for my treatment. If I get any financial aids from CRP, I will use it to modify my environment to increase my accessibility at home. It will help me to be independent. I will teach students at home as a house tutor. From my income, I would be able to repay the loan."*

Except for one respondent, Mr. Jamir, the other participants thought it would be possible to repay the loan. Mr. Jamir said, *“It would be impossible for me to repay any loan greater than 2000.00 taka (USD 24.46). I used to work as a shopkeeper and sometimes as a day labourer before my accident. That time I used to earn between only 50.00 taka (USD 0.61) and 150.00 taka (USD 1.83) daily. Now with this physical condition it won’t be possible for me to do anything other than shop keeping. So, with this little income how would I be able to bear my family costs and repay the loan? Now, my wife might have to work as a daily labourer or as a maid servant.”*

### **Appropriate Time to Receive the Loan**

Among the respondents who wished to receive an interest-free loan, the majority (76.5%) wanted it both during their treatment and rehabilitation period at CRP, and afterwards to start up self-employment in their community. The remaining respondents (23.5%) thought it would be better if they received the loan only after returning to their community.

In the qualitative interviews, respondents also voiced their concerns about the proper use of the loan amount. They suggested that CRP should not distribute the entire amount at one time but in phases. A certain amount could be given at the time of treatment, some more during vocational training and a large sum to start a business after returning to the community. In this regard, Mr. Jalil said, *“If the total money is given at a time, then people might spend it for other purposes, because there are many competing needs, so at the end they won’t have any money to start any income generating activities.”*

Another participant said, *“As I am a tetraplegic person, I have no strength to do anything. I would be grateful if I could get this loan when I will return to my community. I would buy two cows by the loan amount. My son will take care of cattle and sell milk. Thus he will be able to be the bread-winner of my family.”*

### **Repayment Procedures**

Among the participants in the survey, 70.60% suggested repayment by monthly instalments, 17.64% suggested quarterly instalments, while 11.76% preferred yearly instalments.

One respondent, Mr. Rahim said, *“I think I would be benefited from the monthly instalment. It would give me enough time to roll my profit in my business, while it will also check me not to be a defaulter. By weekly profit I will be able to buy more goods*



*for my shop and at the end of each month I will be able to save some money for the repayment."*

Another respondent, Mr. Karim said, *"If I get a chance to pay my instalment quarterly I would be benefited. Quarterly instalment will incur less transportation cost and time to pay my instalment."*

On the other hand, Mr. Rahmat preferred annual instalments, *"As I am a tetraplegic, I would not be able to do anything by myself. Annual instalment would allow my family enough time to pay the instalments."*

Totally, 35.9% of the participants said that it would be helpful if CRP staff were to collect the instalment amount from their homes. The reasons for this were explained well by Mr. Hossain. He said, *"As a wheelchair user it would be extremely difficult for me to come to CRP. On the other hand, if my father comes to pay the instalment then he won't be able to drive his rickshaw-van on that day. So, it would be better if the CRP staff visit our home to collect the instalment."*

Another problem arising from having to visit CRP for repayment was mentioned by Mr. Tomiz, *"To pay the instalment of 1000.00 taka (USD 12.23) I would have to spend 500.00 taka (USD 6.11) as my travel cost which would be an unnecessary burden on me. So, it would be better if CRP's staff visit our home and collect the instalment. Alternatively there should be arrangement through postal or banking service."*

Overall, 36.2% of the participants suggested repayment through post office/postal service, 25.4% suggested repayment through banking channels, and only 2.5% of the participants proposed that they would come to CRP and pay the instalments themselves.

### **Expected Support from the Loan Provider**

People with SCI not only want loans, but also vocational training for themselves or for their family members in order to be able to repay the loans. For example, Mr. Jamil said, *"CRP should not only provide us loan, but also vocational training. I am a wheelchair person. How would I be able to maintain a shop or do any other business? For that reason, CRP needs to provide vocational training to us. This training should be designed to address everything needed to prepare ourselves to run a business with our disability."* More than half (55.88%) of the survey participants said that they needed vocational training, while the remaining did not want it. Some of those who did not want vocational training (70.60%) had prior experience in running

a business. In this regard, Mr. Subir revealed that since he had some experience in running a small business prior to his spinal cord injury, he did not need any further training from CRP. On the other hand, tetraplegic and aged respondents wanted vocational training for their family members: *“My four limbs are affected. So, it’s impossible for me to take any vocational training. If CRP provide sewing training to my wife then it would be helpful for me. My wife could earn money by sewing clothes and would be able to repay the loan easily”*.

## DISCUSSION

The most common causes of SCI are falls from a height and falls while carrying heavy loads on the head which are associated with occupation (Hoque et al, 1999). Thus it was not unexpected to find that most of the study’s participants were involved in occupations requiring manual labour. The 9:1 male-female ratio is also not surprising because the majority of Bangladeshi women work at home and, unlike the men, are not involved in jobs generally associated with SCI (Hoque et al, 1999). The low literacy rate of the respondents came as no surprise since such people are poor and are more likely to be involved in hazardous manual labour. Another study conducted by Hansen et al (2007) found similar facts about individuals with SCI in Bangladesh.

In 2008, the average pre-injury income of people admitted at CRP with spinal cord injury was only 3075.00 taka (37.60 USD) per month, while the total expenditure for each patient at CRP was 22500.00 taka (275.15 USD) per month (CRP Social Welfare Department, 2008). According to Hoque et al (1999), patients stay at CRP for an average of 5 months, ranging from 1-6 months. Thus, the average hospital rehabilitation cost for a person with SCI stands at 112500.00 taka (USD 1375.73). In addition, when operations are needed, the cost is extra. The average operation cost at CRP was 5863.63 taka (71.70 USD), and could range from 500.00 taka to 20000.00 taka (6.11 – 244.57 USD) depending on the type of operation (CRP Social Welfare Department, 2008). However, people with SCI were only required to pay what they could afford. Economic status is assessed by CRP’s social welfare staff who decide on appropriate levels of payment, which range from free treatment to full payment (CRP, 2006). User contributions are an important source of finance and help CRP to operate in a fair and transparent fashion. Even with CRP’s financial support, people with SCI often have to sell or mortgage their property, receive loans from the informal sector at high interest rates, and sometimes even beg for money to

meet other direct and indirect treatment and rehabilitation expenses, such as the costs of medication, the caregiver's expenses while attending on the injured family member in hospital, travel costs, money to feed other family members at home, and lost income opportunity for both patient and caregiver. So, when they return to their community after completing the rehabilitation programme, they find themselves in vulnerable positions through loss of property, jobs and other income options.

In Bangladesh, poor people with SCI often delay hospital admission because of lack of money. One of the participants got admitted at CRP three months after his injury, having spent the intervening period in collecting money for his treatment. It is very important for a person with SCI to get admitted in a hospital immediately after injury, to prevent further damage and for better results. The delay can often be life-threatening. Proper emergency management enhances both survival and neurological integrity (Somers, 1992).

Disbursing adequate amounts of the loan at the appropriate time might be the key to a successful interest-free loan programme. CRP covers all or most of the direct rehabilitation costs for poor individuals with SCI, but often they still resort to taking high-interest informal loans, mortgaging or selling their assets, and sometimes begging for money to meet indirect rehabilitation costs and to fund their families. Thus, adequate loan amounts paid out during the rehabilitation period might be able to save their assets, ensuring successful rehabilitation. Since the loan would have to be repaid, a suitable sum should also be given for them to start any small business in their community after the hospital rehabilitation. This was suggested by the majority of the respondents. Lack of initial capital was identified as a major hindrance by re-employed individuals with SCI following CRP's rehabilitation and vocational training (Hansen et al, 2007).

Most of the individuals with SCI in Bangladesh who are poor and involved in occupations requiring extensive manual labour, do not get back their jobs after rehabilitation (Hansen et al, 2007). In this context, it is important to arrange appropriate vocational training for individuals with SCI and/or their family members so that they can start small businesses after returning to their community. Instalment amounts and number of instalments per year need to be decided carefully, in consultation with the people who have taken loans, so that there is no undue pressure on them. Some preferred to pay in monthly instalments, some preferred quarterly instalments while others preferred yearly

instalments. Paying instalments could work out expensive and troublesome if they were required to visit the rehabilitation centre to do so. On the other hand, collecting instalments from their homes would not be cost-effective for the rehabilitation organisations. The alternative could be to make payments through banking channels or the postal service. However, the most efficient and effective idea would be for a rehabilitation organisation to tie up with micro-credit NGOs or commercial banks who would agree to provide interest-free loans as part of their corporate social responsibility. This blend of expertise would make the programme successful.

## CONCLUSION

Rehabilitation of the individual with SCI is a lifelong process that requires readjustment to nearly every aspect of life (Adler, 1996). Though delayed hospital admission is harmful and could be life-threatening, poor people with SCI often delay hospital admission because of lack of money. Their families often find themselves in an extremely vulnerable position, having lost their source of income and having to manage treatment and rehabilitation costs. Bangladesh still pursues a welfare model of disability without paying attention to the rights of people with disabilities. These people do not even have access to regular micro-credit (The Daily Star, 2008). Financial aid in the form of interest-free loans for the treatment and rehabilitation of poor people with disabilities could be effective in saving their families from bankruptcy. Proper mechanisms for loan disbursement and repayment need to be in place to ensure that a sustainable revolving fund can serve many people. The loan providers also need to step in to provide/arrange appropriate vocational training for people with disabilities and/or their family members, in order to enable them to repay the loan instalments.

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