

IMPACT OF SERVICES FOR PEOPLE WITH SPINAL CORD LESION ON ECONOMIC PARTICIPATION

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ABSTRACT

In Bangladesh, economic participation is crucial for disabled people, as there is no social security for them in Bangladesh. However, economic participation receives little attention from service providers and policy makers who view disability as a medical problem and focus on medical interventions. They give little consideration to social and economic support for disabled people. Only a few Non-Governmental Organisations (NGOs) provide training and employment for disabled people. The Centre for the Rehabilitation of the Paralysed (CRP) is the only organisation in Bangladesh to provide specialised services for people with spinal cord lesion (SCL). CRP focuses on the whole person rather than treating the person's impairment alone. Interventions of CRP include treatment within hospital, as well as social and economic rehabilitation in the community (1, 2).

This paper illustrates the barriers to economic participation that government policy and practices fail to address, and compares them with the holistic approach taken by CRP. Further, a list of suggestions to improve economic integration of disabled people in Bangladesh is also presented.

INTRODUCTION

Participation in paid work is vital during adulthood in most societies. Economic participation covers both formal and informal economic activities. Formal economic participation includes paid employment in public and private sectors, which is regulated by laws, and the informal sector covers self-employment or unpaid work within the home. In Bangladesh many people are self-employed rather than employed in the formal sector (3). Paid work is a matter of economic survival for disabled people and their families (4). However, they are often excluded from work because they are viewed as unable to work due to their physical impairment and/or psychological consequences (5, 6).

Disabled people are among the poorest of the poor in Bangladesh (8). Women are generally worse than men and they are engaged in unpaid household work (9). As there are no social security benefits for disabled people, and no financial help to compensate the additional costs of living with impairments, paid employment is vital for their survival (2). A study commissioned

by Department for International Development (DFID-UK) in 1999 to evaluate the impact of services of CRP revealed that 75 percent of users of CRP's services come from the poorer sections of society (10).

The population of Bangladesh in 1996 was 122 million, out of which 54.6 million people were employed. Of all employed people, 30 percent were self-employed, 12 percent were employed in the formal sector, 18 percent were employed as daily labour and 40 percent were employed in unpaid work. Out of all people employed in unpaid work, 10 percent were employed in household work (3). Some studies in Bangladesh suggest that prejudice against disabled people contribute to low numbers of disabled people in paid work (2, 11, 12, 13). Many disabled people are even denied Micro-Credit (non-formal loan for poor people) for income generation (13).

This study identifies barriers to employment and economic participation of people with SCL and recommends measures to improve the economic participation of disabled people

METHODOLOGY

The approach to this study was participatory, using principles of emancipatory research (14, 15). People with spinal cord lesions played a key role in developing methodology. It was considered vital that their views were presented as accurately as possible. Forty-eight respondents were involved as research participants for face to face interview. Half were from Centre for the Rehabilitation of the Paralyzed (CRP), selected through stratified random sampling and the other half were from general hospitals selected through quota sampling. In addition to this 16 participants were involved in focus group sessions, half of whom were from CRP and the other half from general hospitals, all selected using purposive sampling method. The participants were aged between 10-59 years and all had received services between 1994 and 1999. The participants lived in the Dhaka, Narayanganj, Gazipur, Manikgonj, Munshigonj and Narshingdi districts of Bangladesh. Gender and severity of injury were considered to be key selection criteria. Data were generated through semi-structured face to face interviews with 48 participants on 3 occasions and from focus group discussions with 16 participants. In addition, background information on all 64 participants was elicited at the outset from structured interviews. A team of eight 'research associates' conducted the research constituting the non-disabled author of this paper, four people with spinal cord lesions (two from CRP and two from general hospitals), two CRP staff, and one non-disabled person who was selected from the community. The research associates arranged a workshop to determine the best method of data collection to be used. During this workshop decisions were also made about issues to discuss with participants. The research associates conducted the interviews and analysed the data to identify themes concerning economic participation.

RESULTS AND DISCUSSION
Table 1: Gender of respondents with SCL

Gender	CRP %(no)	General hospitals %(no)	Total %(no)
Male	50(16)	50(16)	50(32)
Female	50(16)	50(16)	50(32)
Total	100(32)	100(32)	100(64)

Table 2: Age at injury

Age (in years)	CRP %(no)	General hospitals %(no)	Total %(no)
10-14	09(03)	06(02)	08(05)
15-25	41(13)	34(11)	38(24)
26-39	31(10)	37(12)	34(22)
40-59	19(06)	22 (07)	21(13)
Total	100(32)	100(32)	100(64)

Two-third of the respondents was injured between 15 and 39 years. The mean age of CRP respondents was 31 years, while that of general hospital respondents was 33 years.

Table 3 : Severity of injury

Severity of Impairment	CRP %(no)	General hospitals %(no)	Total %(no)
Complete Tetraplegia	25(08)	25(08)	25(16)
Incomplete Tetraplegia	15(05)	15(05)	15(10)
Complete Paraplegia	25(08)	35(11)	30(19)
Incomplete Paraplegia	35(11)	25(08)	30(19)
Total	100(32)	100(32)	100(64)

Thirty percent of general hospital respondents had complete paraplegia in contrast to 25 percent of CRP sample, while 35 percent of CRP sample had incomplete paraplegia in contrast to 25 percent general hospital sample.

Table 4 : Classification of respondents according mobility aids used

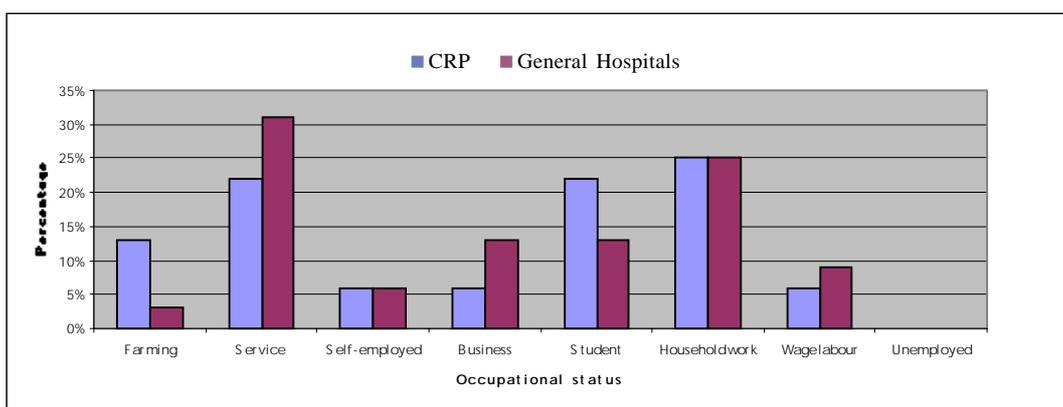
Mobility aids	CRP %(no)	General hospitals %(no)	Total %(no)
Wheelchair	47 (15)	06(02)	26(17)
Walking Stick/Crutch	03 (01)	12 (04)	08(05)
Walking without Aids	44 (14)	38 (12)	41(26)
Without Mobility Aids	06 (02)	44 (14)	25(16)
Total	100(32)	100(32)	100(64)

Forty seven percent of CRP sample had wheelchairs as against only 6 percent from general hospitals.

Table 5: Respondents' level of education

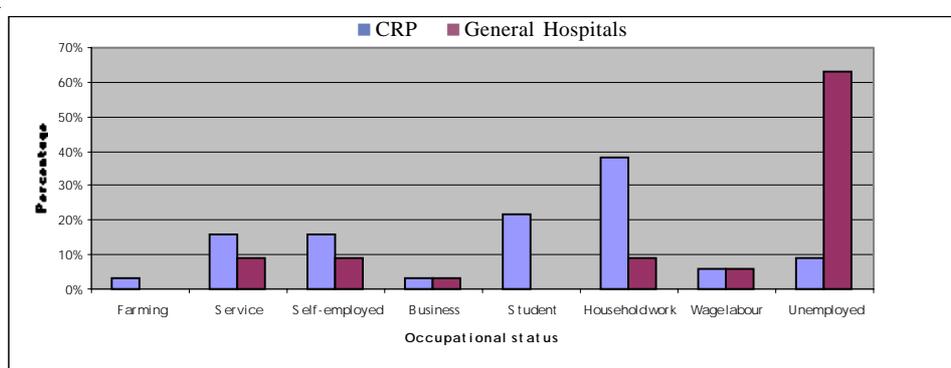
Education	CRP % (no)	General hospitals %(no)	Total %(no)
No Education	19 (06)	21 (07)	21(13)
Primary School	21 (07)	33 (10)	27(17)
High School	41 (13)	27 (09)	34(22)
GCSE and above	19 (06)	19 (06)	19(12)
Total	100(32)	100(32)	100(64)

Figure1: Participation in economic activities before injury



Before injury more respondents from CRP did farming (13%) or were students (22%). But more respondents from general hospitals were in business (13 %) and worked as waged labours (9 %). None of the participants from CRP or general hospitals were unemployed/inactive before impairment. They were involved either in formal (paid) work or informal (domestic) work or were students.

Figure 2: Participation in economic activities after injury



Sixty-three percent of respondents from general hospitals were unemployed/inactive whereas only 9 percent of participants from CRP were in this category. Only 9 percent of the general hospital sample were involved in service as against 16 percent of CRP sample. There was a sudden drop of 22 percent of general hospitals sample from services in contrast to only 6 percent drop from CRP sample after injury. Sixteen percent of CRP sample was involved in self-employment in contrast to only 9 percent of general hospitals sample. Thirty eight percent from CRP sample were involved in household work, in contrast to only 9 percent of general hospitals sample. After injury a higher number of CRP sample were involved in household work in contrast to before their injury, whereas from general hospitals involvement in household work dropped from 25 percent to 9 percent. Twenty two percent from CRP were students, whereas there were no students among respondents from general hospitals. None were withdrawn from education after injury amongst CRP respondents whereas none continued in education from general hospitals after their injury. Three percent were in business both in CRP and general hospitals. There was a drop of 10 percent from general hospital sample for business category compared to only 3 percent drop in CRP sample. There was no difference in wage earning labour between samples from CRP and general hospitals.

More CRP respondents were able to participate in service, self-employment, household and educational activities than respondents from general hospitals. It was possibly because of the provision of mobility aids, vocational training and micro-credit support. CRP's therapeutic support and health education also could have helped respondents continue their activities

without having to depend on others. For general hospitals groups there was a higher dependency on others (2).

BANGLADESH GOVERNMENT POLICIES FOR PARTICIPATION OF DISABLED PEOPLE IN ECONOMIC ACTIVITIES

At the end of 1992, the Economic and Social Commission for Asia and the Pacific (ESCAP) re-designated 1993-2002 as a second decade of disabled persons for Asia and the Pacific region (16). Disability was officially recognised by the government of Bangladesh with signing of the proclamation of ESCAP on 22nd August 1993 (17). In the early 1990s NGOs working with disabled people in Bangladesh formed a National Forum of Organisations Working for Disabled (NFOWD) (18). Since then groups for 'equal opportunity' and 'full participation' of disabled people have been lobbying with the Government (12, 17, 19, 20, 21).

The Government of Bangladesh passed the National Policy for Disabled People in November 9, 1995 (12). In the Disability Policy, sections 15, 17, 20 and 29 of the Bangladesh's constitution emphasise 'equal opportunity and full participation' of disabled people. These sections describe access to 'basic rights' such as food, clothing, shelter, education and health care. They also have assurance of equal opportunities in employment. In the policy, the government has acknowledged the International Declaration of Human Rights for Disabled People (1975) and the ESCAP declaration (1993) for 'equal opportunity and full participation' of disabled people (16). The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (22) were also included in the National Disability policy.

However, the implementation of these Government commitments is very slow, to the extent that they remain largely theoretical and are not in practice (17). For example, after adaptation of the National Policy for Disabled People, there have been few changes in terms of development of any services for disabled people or in areas of institutional discrimination such as education and employment (17, 19, 21). The government has also adopted the policy of a 10 percent quota for employment of disabled people (12). But less than one percent disabled people are involved in paid employment (23). The situation of disabled women in Bangladesh is even worse because fewer women present for interventions.

Among participants in this study, 75 percent were not aware of the government job-quota for disabled people. Those who were aware of it felt it would not bring about any changes in the job market for disabled people because there is no legal penalty if they fail to comply (11). In addition, there are no measures to promote employment of disabled people, such as making available vocational training, mobility aids, education, accessible work environment or information about job vacancies. As a result, the quota remains only as a commitment on paper. Little is done in practice to help disabled people take up opportunities in the job market

(2, 11). So far the government has provided vocational training for only two organisations in Bangladesh on trades such as basket making, carpentry, weaving etc (24). However, these trades are not in demand and does not help in improved 'productivity and self-reliance' (25). These training organisations are also under-utilised.

Some clients from CRP who had received services over 20 years could not find re-employment in occupations that they had prior to their injury. They were employed in the formal sectors of employment, agriculture or were students. Many people with SCL were however self-employed after their injury (26). This is due to CRP providing support to them through vocational training that encouraged involvement in self-employment. To obtain a formal job or to continue education requires support from government and private employers. To undertake paid employment attitudinal barriers as well environmental barriers need to be changed (11, 23). Opportunities for disabled people to gain and retain employment could be enhanced if changes in employers' perception of disability are made, barriers to employment in terms of information, physical access and adaptations are removed, employment is subsidised and created (27). Generally disabled people need support through micro-credit programmes also to be able to become economically active or continue their education.

SERVICES FOR PEOPLE WITH SCL IN BANGLADESH

There are no specialised hospitals for comprehensive rehabilitation of people with SCL in Bangladesh apart from one non-governmental organisation, CRP (28). Other service providers for people with SCL as well as other impairments adopt a medical model of disability (9). They offer services only in their hospitals or at their clinics. There is little opportunity for dialogue between users and service providers. When people with SCL are discharged, there is little, if any, follow-up (2). They become dependent on family members and are unable to participate in community activities. Mobility aids are not often available, which further restricts the person's ability to be an active member of his/her community (18).

In contrast, CRP offers services focussed on the person's whole life rather than treating him as a person with impairment (10). Though initially CRP was started as a specialised unit in a government orthopaedic hospital, over the years the types of services provided have changed, through user involvement in service design and provision. Support is also extended once the person goes back to living in the community. Families are encouraged to become active participants in the rehabilitation process. CRP (1, 2) facilitates community awareness activities as well as education and involvement of community members in support networks.

BARRIERS EXPERIENCED BY PEOPLE WITH SCL IN ECONOMIC PARTICIPATION

Given below are themes that emerged from the interview and focus group sessions.

Barriers of access for employment or economic activities

Misconceptions of many people that disabled people have limited abilities affect their opportunity to enter the job market. Employers focus on the physical impairment and assume that wheelchair users cannot work. They do not consider work environment for accessibility for wheelchair users (11). This issue is not unique to Bangladesh. For example, in the UK disabled people might be discriminated against in terms of appearance, as they may not have a 'conventional body shape' (29). A third of the 26 health authorities in the UK sampled in a study chose not to employ disabled people because of misconceptions about their abilities (30).

Barriers in retaining work

Disabled people generally had negative experiences of attempting to keep or find employment. Many were employed before their impairment but found that after their impairment they were often considered 'unemployable' (31). In the UK, one in six people who were or had been economically active experienced discrimination in a work related context (32). Of these, 42 percent report that they have been discriminated against by an employer or a potential employer. The employment situation of Bangladesh is not directly comparable with UK because few disabled people continue working in mainstream job market after their impairment. However, the comparison confirms that disabled people are discriminated against in the job market across the world.

Barriers to obtain appropriate work

Some respondents who had higher secondary level education and were previously employed looked for some jobs related to their previous skills. They had difficulty in getting a job in which they had previously worked. Employers focus on the physical impairment. They seldom make adjustments to the environment for the disabled person to work. Employers put more importance on work output and long hours of work. Many employers do not see a value for disabled people in jobs that they can do perfectly well even after their impairment.

Barriers in career prospects

Attitudes of seniors and colleagues towards disabled people limited their career development opportunities. It also acted as a threat to job retention. No participant reported good career prospects in their current jobs. They felt that employers ignore their career prospect due to

their physical impairment although disabled people have the right to promotion, further education and professional development training.

Barriers to receive appropriate wages

Respondents who were employed for pay found that some of their employers perceived them as 'sick', and 'less productive'. Some respondents were asked to receive less remuneration because of their impairments. Centre for Services and Information on Disability (CSID) (31) also reported similar findings. However, there were mixed responses about discrimination in salary structures. Some respondents did not experience any discrimination in salary structure. There was a report of harassment from supervisors and delay in receiving salary. The same person did not also get any other privileges provided by the government. Yet another respondent had good experiences from her employer and found that the systems were equal for all employees. These reports suggest that misconception about ability of disabled people vary from people to people in the Government or private sector, and sometimes cause discrimination in salaries.

Barriers due to discriminating attitude of employers and colleagues

Another respondent, who worked in a government hospital, found that her annual increment was denied after acquiring her injury. Before her injury she was awarded an annual increment, which was added to her monthly salary on a regular basis. Her salary was halved because she could not move without a wheelchair. Some respondents experienced negative attitudes from senior officers rather than their colleagues. They did not view them as 'worthy', even though they do not have any problems working. Some respondents experienced lack of support from their colleagues in their work place. These reflect the public attitude towards disabled people. Able-bodied employees felt disabled people are less worthy to be employed. There were also reports of disrespect and teasing of disabled women and girls (31).

Medical barriers in job market

In the current job market employers often expect applicants to have certain physical attributes. Respondents who had physical limitations felt that the expectations concerning physical attributes restricted their opportunities to get paid employment; even though they met the other criteria for the jobs they had applied for. Employers focussed on physical characteristics rather than on actual requirements for the job when considering a disabled person for employment. They also had the problems of mandatory requirement of medical certificates to enter into formal job market (6, 11).

Barriers due to lack of appropriate skills

Some respondents said that there were limited training opportunities they could access for paid employment or self-employment. Available opportunities for jobs include traditional trades such as weaving, sewing, and carpentry. Even though the goal is to rehabilitate disabled people with useful job skills, there was no assessment to see if training would be of any use for economical solvency. On many occasions these training programmes were found unproductive (33).

Barriers due to lack of educational qualification

Education is the key to take advantage of new technologies both at home and work. International Labour Organisation (ILO) reports that new technology has reduced the demand for unskilled and semi-skilled labour and it has gradually reduced the opportunities for disabled people (34). Some respondents pointed out that they do not qualify for the present job market, as they are illiterate and do not have any appropriate skills (11). Almost all jobs need some basic education as well as skills and experience, which they lack. In addition, disabled people have no access to jobs that are advertised, due to poor accessibility to information or employers' choice of able-bodied people. Disabled women particularly experience greater difficulties gaining paid employment. This is also because girls are less likely to attend primary or secondary school, or undergo any training. Disabled girls are also limited in their range of education probably because people have lower educational expectations of them (31).

Barriers due to inaccessible work environment

Many participants who had jobs expressed concern that their work environment was inaccessible for them as wheelchair users and/or that the 'production process' was inaccessible. It was worse for those who used any kind of mobility aid. They also reported that employers are not interested in making the environment accessible for disabled people because they think that disabled employees are less important than non-disabled employees. There are no laws in Bangladesh that require buildings and other facilities to be accessible. Employment opportunities are restricted because of inaccessible physical and social environments. Many people with SCL cannot take part in paid employment because of inaccessible work environment.

Barriers due to inaccessible transport systems

Many respondents reported on inappropriate transport system. When no provision is made for accommodation near the work place for disabled people, the majority become homebound. The Bangladesh transport policy ignores disabled people altogether.

FACTORS THAT ENHANCE ECONOMIC PARTICIPATION

Job based training

CRP offered job based training to disabled people and found that both employers and employees were satisfied with the outcome. Many trainees got jobs after completion of the training and their employers also were happy with their performance.

Market led training

Participants who were clients of CRP received vocational training of their choice. They underwent training in the area that interested them and some found jobs based on the skills they had learned. When disabled participants gained appropriate skills they were more confident in their ability to work. Ironically, some disabled people reported that prejudice and discrimination actually drove them to greater achievements.

Accessible work environment

Most participants view inaccessible work environment as a major barrier to participate in the job market. Those who continue their job after spinal injury experience great stress due to structural barriers. In contrast some participants' workplace were made accessible for wheelchair users.

Financial support through micro-credit

Participants who received support through micro-credit were generally happy about being given this opportunity.

CONCLUSIONS AND RECOMMENDATIONS

Disabled people experience multi-sectoral barriers to participate in paid work. One of the main barriers is because the employer adopts a medical interpretation of disability. They perceive disabled people as inactive, useless and unworthy, hence excluding disabled people from the job market. However, disabled people view disability as a social problem, as listed below:

- Attitudinal barriers that prevent access to employment, retention of work, obtaining appropriate work, career prospects, discriminatory attitude of employers, supervisors and peer groups.
- Institutional barriers that include mandatory requirements of medical fitness certificate for employment, lack of inappropriate training and lack of education opportunities.

- Structural barriers include inaccessible work environment and inaccessible transport systems.

Beyond their physical impairment these barriers perpetuate a disabling society in which disabled people are discriminated against and often excluded from economic participation. On the other hand some positive measures such as job based training, market related training, accessible work environment and support through micro-credit, promote effective participation of disabled people in paid work. Government and developmental organisations must promote an inclusive policy that ensures disabled people obtain access to the mainstream job market and compete with non-disabled people. The following recommendations would be of help to combat barriers for disabled people:

- Adoption of inclusionary policies and practices that foster inclusion of disabled people in mainstream economic participation (35).
- Legislation promoting equality and full participation implemented through enforceable laws.
- Medical or physical fitness for employment should be replaced with the individual's capacity to work when given the access they need.
- Government should provide subsidies available to help employers make work environments accessible.
- Employers should prioritise making work environment accessible, provide accommodation for disabled employees near the workplace and accessible transport for easy access to workplace.
- There should be mechanisms to prevent discriminatory remuneration practices.
- Information regarding job vacancies, training etc. should be accessible to all disabled people.
- A recruitment allowance should be paid to cover travelling expenses and cost of lodgings to facilitate participation in the recruitment.
- Employers should include a disabled representative in the recruitment process.
- Peer support should be provided to disabled people to enhance their self-esteem and give them confidence to enter the job market.
- All disabled people should have equal opportunities to gain promotion based on their education, training, skills, experience and merit.
- The government should provide subsidised training and education for all disabled people, in an environment where job-based training is available.

- Disabled employees should be provided with allowances to cover the cost of aids, adaptations and assistance.
- Employers should offer flexible working hours to disabled employees and other employees if appropriate.
- Employers should educate and train the staff about understanding of disability.

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