

Livelihood challenges for extremely poor disabled people in the southwest coastal region of Bangladesh

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ABSTRACT

This paper presents findings from qualitative and quantitative research into the challenges faced, and achievements made, by extremely poor disabled people as they undertake income-generating activities in the southwest coastal region of Bangladesh. Research participants were from a Save the Children International (SCI) sponsored poverty reduction programme, with additional focus group discussions with members of Action for Disability and Development (ADD) International. The findings highlight a number of important issues arising from the experiences of disabled people and their families, which have implications for policy makers and practitioners working to facilitate poverty reduction amongst this group of the extreme poor.

The research showed that about 12 percent of extremely poor people suffered from some kind of disability. Of these the largest group (33 percent) were those suffering from a physical disability of some kind. About 13 percent reported a visual impairment, 9 percent experienced hearing and speech difficulties and 9 percent had learning difficulties. About 33 percent of disabled people in the study had multiple impairments. The high frequency of disability amongst the extreme poor draws attention to the need to mainstream support and protection for disabled people within anti-poverty policy. Thus efforts to reduce extreme poverty will necessarily include measures to protect and support the disabled.

However the research also showed that in Bangladesh many extremely poor disabled people are still excluded from the social and economic activities that would allow them to graduate from poverty. This exclusion could be reduced if social protection coupled with resources for income generation were more effectively targeted. In addition policy measures to improve support and protection for disabled people in work and small businesses, with improved disability legislation, and better adherence to existing legislation, is urgently needed.

The research showed that only about 31 percent of extremely poor disabled household heads were receiving government safety net benefits, with only about one half of these receiving the disability benefit. A significant proportion of extremely poor people with disabilities go without government safety-net benefits altogether.

In addition to the need for better access to social protection, the study showed that better access to quality health provision, better availability of appropriate assistive devices, more inclusive infrastructure and building, public transport and schooling are also urgently needed for disabled people in Bangladesh.

The research identified how widespread discrimination against the disabled in Bangladesh creates unnecessary, yet serious barriers to life improvement for these people, especially when they are also burdened with extreme poverty. There is an urgent need to support a variety of social and political activities in order to challenge the stigmatization and exclusion of extremely poor disabled people in Bangladesh, especially in rural areas.

Progress has been made in improving the lives of many extremely poor disabled people in Bangladesh, including positive results seen from the activities of the Save the Children programme examined here. However our study suggests that better support and protection for extremely poor and disabled people in Bangladesh, across a wide range of policy issues and areas is urgently needed. The study also provides evidence that if effective support and protection were achieved, it would allow many extremely poor disabled people to not only live more healthy and happy lives, but to also make a greater contribution to economic and social progress in the country as a whole.

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ACRONYMS

ADA: American with Disabilities Act

ADD : Action for Disability and Development

BPDW: Bangladesh Persons with Disability Welfare Act
CRPD: Convention on the Rights of Persons with Disabilities

DDA : Disability Discrimination Act

DFID : Department for International Development

EP : Extreme Poor

FGD : Focus Group Discussion
GOB : Government of Bangladesh

HEFS : Household Economic and Food Security

IGA : Income Generating Activities

NCCD : National Coordination Committee on Disability

NGO : Non Government Organization SCI : Save the Children International TFA : Temporary Financial Assistance

UN: United Nations

VGD : Vulnerable Group Development VGF : Vulnerable Group Feeding WHO : World Health Organization

1. INTRODUCTION

Since 2009, Save the Children International (SCI) has implemented the Household Economic and Food Security (HEFS) project across six *upazilas* in the two coastal districts of Khulna and Bagerhat in the southwest of Bangladesh. The devastating impact of Cyclone Alia in this area in 2009 provided impetus for the project which was supported by a scale fund grant from UKAID-SHIREE¹, and aimed to help 70 percent of about 15,000 extremely poor beneficiary households to move out of poverty. Graduation would be achieved by strengthening income sources and diversifying employment opportunities through a variety of interventions.

Temporary Financial Assistance (TFA) to the most vulnerable households was one of the services provided by the project. The targeted group included people affected by physical or mental disability, old age, and those lacking the capacity improve their livelihoods. TFA provided a 300 taka (US \$3.67) monthly benefit to households who had already been involved in government safety net programmes, and 600 taka (US \$7.34) per month to those who had not received such support. As of March 2012 there were 1,666 TFA households. Of these, 12 percent (202) had at least one household member who was considered physically or mentally disabled.

While the monetary assistance from TFA helped provide some protection for extremely poor recipients, the benefits were usually not sufficient to create new income generating projects, and therefore these recipients tended to remain poor. In order to facilitate more sustainable graduation from poverty, SCI introduced income-generating activities (IGAs) to 390 households who had previously received TFA. This included IGAs for people with disabilities, providing opportunities in crop cultivation, crab cultivation, rickshaw pulling and other small businesses.

This paper draws from qualitative and quantitative research into these extremely poor households, who were also affected by disability, and explores the problems faced by, and the transformational effects on, extremely poor disabled people as they became involved in the project's income generating activities (IGAs).

Some disabled people were too severely disabled to work and in these cases relatives or neighbours operated IGAs on their behalf. Even when beneficiaries were able to work to some extent, they still often relied on support from family and friends. This introduced an unusual dynamic into transfers for IGAs, with field staff required to identify activities appropriate in the disabled person's particular circumstances.

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¹ The Economic Empowerment of the Poorest (EEP)/shiree programme is a partnership between the UK Department for International Development (DFID) and the Government of Bangladesh (GoB) under the Rural Development and Cooperative Division (RDCD) of the Ministry of Local Government, Rural Development and Cooperatives (LGRD) to lift 1 million people out of extreme poverty by 2015. EEP/shiree provides resources to national and international NGOs working in Bangladesh through two challenge funds: the Scale Fund and the Innovation Fund. The Scale Fund provides NGOs opportunities to take large numbers of people out of extreme poverty using tried and tested methods. The Innovation Fund challenges NGOs to design and implement innovative approaches to reducing extreme poverty in urban and rural areas of Bangladesh. Save the Children has been implemented with a scale fund grant from UKAID-SHIREE.

Three different qualitative methods were used in the study: life histories, in-depth interviews and focus group discussions. These methods helped researchers understand the range and context of livelihood challenges facing extremely poor disabled people, and the complex forms of deprivation they experienced. This qualitative research was supplemented by quantitative Save the Children baseline data collected in 2009 and 2010 and a disability screening survey conducted by the team in early 2012 to identify types of disability, causes of disability, difficulties doing daily activities, and the use of assistive devices. Supplementary questions about the project intervention and access to social safety nets were also included in these surveys.

The definition of disability used by the Bangladesh Persons with Disability Welfare Act 2001 was adopted for most of this study although there were some differences – such as an age cut off difference between the SCI baseline survey and our disability screening survey. We also applied the Sustainable Livelihoods Approach in our analysis of the livelihoods of extremely poor disabled people. Our overall aim was to inform policy and practice to reduce extreme poverty among persons with disabilities, and their families, and help promote active community participation.

The existing literature on poverty and disability shows that disability and poverty are linked, and for poverty reduction to be successful disabled people need to enjoy equal rights with the non-disabled (see Lee, 1999 cited in Yeo, R. 2001). Several studies show the disabled are commonly excluded, isolated, harassed, stigmatized and denied their basic rights and entitlements. As a result they experience higher rates of poverty (see for example DFID, 2000; World Bank and ADB, 2002, in Thomas, 2005) and also have weaker social networks. These combine to create serious obstacles to escaping poverty or constructing sustainable livelihoods.

Despite these challenges the need to focus on improving the livelihoods of the disabled has not been sufficiently addressed in development and poverty reduction initiatives. Several studies have revealed that, both in developed and developing countries, working age persons with disabilities experience significantly lower employment rates and much higher unemployment rates, and therefore have far lower rates of labour market participation than persons without disabilities (OECD, 2010 cited in WHO 2011 and World Bank, 2008). Even though the extreme poor in general have limited employment opportunities, the disabled extreme poor are particularly disadvantaged.

It is widely recognized that employment and income generation are key factors for empowering and promoting the inclusion of people with disabilities into society (DFID 2000). Some studies (for example DFID 2000, WHO 2011) have indicated that many people with disabilities have proven their capability in various sectors. Across the world, people with disabilities are entrepreneurs and self employed workers, farmers and factory workers, doctors and teachers, shop assistants and bus drivers, artists, and computer technicians (Domzal et al 2008, cited in WHO 2011). Thus if effective support and protection in employment and income generation are achieved for disabled people, many extremely poor disabled people will be allowed to not only live more healthy and happy lives, but will also make a significant contribution to economic and social progress across society.

In Section 2, below, we outline the context of disability amongst the extreme poor in Bangladesh, and the particular challenges in promoting sustainable livelihoods for this group. In Section 3 we move on to discuss the methodology of the study with a brief socio-demographic description of the study population, before, in Section 4, describing the challenges we identified in maintaining and operating income-generating activities. In Section 5 we explore the impact of the different livelihood development interventions on disabled extreme poor households. We finally conclude in Section 6 with programme and policy recommendations.

2. THE LIVELIHOODS OF THE DISABLED EXTREME POOR IN BANGLADESH

Defining disability is complex and controversial and there is no universally agreed definition. However, William (2001) (cited in Grech, 2009) states that for measurement and policy purposes (e.g. state eligibility for welfare provision) definition is necessary.

The World Health Organization (WHO) defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon reflecting an interaction between features of a person's body and features of the society in which he or she lives" (WHO and The World Bank, 2011).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) defines Persons with Disabilities as those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (WHO and The World Bank, 2011).

The Bangladesh Disability Discrimination Act, 1995 (DDA) (cited in Sultana, 2010) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

Similarly for the Americans with Disabilities Act (ADA), 1990, the term 'disability' means with respect to an individual, a physical or mental impairment that substantially limits one or more of the major life activities of such an individual, a record of such an impairment or being regarded as having such an impairment (Sultana 2010).

Bangladesh Persons with Disability Welfare Act (2001) defines disability as: "...any person who:

- 1) Is physically crippled either congenitally or as result of disease or being a victim of accident or due to improper or maltreatment or for any other reasons became physically incapacitated or mentally imbalanced and as a result of such crippled-ness or mental impaired-ness has incapacitated become either partially or fully and is unable to lead a normal life.
- 2) 'Visual impaired' means any person who has no vision in any single eye or in both the eyes or visual acuity not exceeding 6/60 or 20/200 (Snellen) in the better eye even with correcting lenses or limitation of the 'field of vision' subtending an angle of 20 (degree) or worse.
- 3) Physically handicapped refers to person who has lost either one or both the hands or lost sensation partly or wholly of either hand or it is so weaker in normal condition that the situations stated under sub-section I (a) and (b) are applicable to his case or lost either one or both the feet or lost sensation partly or wholly of either or both the feet or it is so weaker in normal condition that the situations stated under subsection I (a) and (b) are applicable to his case has physical deformity and abnormality or has permanently lost physical equilibrium owing to neuro-disequilibrium or has 'hearing impairment' meaning one's loss of hearing capacity in better ear in the conversation range of frequencies at 40 decibels (hearing unit) or more or damaged or ineffective otherwise or has 'speech impairment' meaning loss of one's capacity to utter or pronounce meaningful vocabulary sounds or damaged partly or wholly or dysfunctional.
- 4) 'Mental disability' means one whose mental development is not at par with his chronological age or whose IQ (Intelligent Quotient) is far below the normal range or has lost mental balance or is damaged partly or wholly or has multiple disabilities that is one who suffers.

So according to the Persons with Disability Welfare Act, disability means physical, mental or intellectual impairment due to which a person cannot participate in normal day-to-day activities. "People with disability" refers to a people who suffer from one of these physical, mental or intellectual impairments.

Disability in Bangladesh

As in many other developing countries, in Bangladesh people with disabilities tend to be neglected and as a result are inadequately protected or supported. Several studies in Bangladesh (CSID, 2002, Sultana, 2010) show how disabled people often live in unfriendly and hostile environments, encounter non-cooperation, ill treatment, neglect and hostility in their families, in communities, in wider society, and in government institutions. They are often deprived, not only of social and political needs, but also basic human needs. This neglect is compounded by a lack of availability of quality services for people with disabilities which could otherwise ensure that they were able to participate in the mainstream development activities. Their mobility is also seriously limited by traditional patterns of building and road construction.

The WHO estimates that there are more than 12 million persons with disabilities living in Bangladesh who currently receive little or no assistance (CSID, 2002). 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.

The Constitution of the People's Republic of Bangladesh guarantees human rights and equality in all respects: political, social, religious, education and employment, irrespective of race, caste, sex, ethnicity and disability. It has numerous provisions that obligate the government to protect the rights and dignity of all citizens of the country equally without any bias (Articles. 10, 11, 15, 17, 19, 20, 21, 27, 29, 31, 32, 36, 38 and 39) (see also Sultana, 2010).

In 2001 the Parliament of Bangladesh enacted The Disability Welfare Act (DWA) 2001 (also known as Bangladesh Protibondhi Kollyan Ain (BPKA)) whereby rights of persons with disabilities received statutory recognition for the first time in the history of country. This act is primarily welfare-based and emphasis is given to the impairment of the individual, but not on social and environmental barriers.

Table 1, below, shows the various acts and initiatives intended to ensure dignity and to protect the interests of citizens of Bangladesh with disabilities. For example: in 1993 and in 2000, The National Coordination Committee on Disability (NCCD) and The National Foundation for the Development of Disabled Persons (NFDDP) were established under the Ministry of Social Welfare. In 1995, The National Policy on Disability was approved outlining guidelines for prevention, identification, education, rehabilitation, research and management of the national program. In September 2006 The National Action Plan for persons with disability was approved by the National Coordination Committee on Disability (constituted under DWA 2001).

Table 1. Bangladesh policy for people with disability

Year	Policy developments
1993	National Coordination Committee on Disability established under the Ministry of Social
	Welfare
1995	National Policy on Disability approved outlining guidelines for prevention, identification,
	education, rehabilitation, research and management of the national program
1996	Action Plan on Disability approved outlining the plan for the implementation of the
	National Policy – this plan has not yet been fully implemented
2000	National Foundation for the Development of Disabled Persons (NFDDP) established under
	the Ministry of Social Welfare
2001	Disability Welfare Act passed by Bangladesh Parliament
Source: 1	Bangladesh Protibandhi Kallyan Somity cited in Sultana, 2010

While this legislation is a positive step in protecting the rights and ensuring the dignity of disabled people there are still many remaining problems. For example, although the government declared a 10 percent employment quota across all sectors for orphans and people with disabilities about two decades ago, this has never been properly implemented. This is partially explained by a lack of awareness among employers about the potential of disabled people. However there are also contradictory employment policies. For example, according to the Recruitment Rules under the Government of Bangladesh (bidhiboddho protisthan shomuhe chakurir jonno adarsha probidhanmala - chapter 2, clause 3, section 3, subsection A (ka)) a candidate may be recruited for a post if he/she is certified as medically fit. On these grounds candidates with disabilities who would otherwise qualify are often not considered for employment in government, in autonomous or in statutory bodies (Sultana, 2010 and Disability Rights Watch Group, 2009). This kind of exclusion is a common experience for people with disability in Bangladesh, regardless of their educational background.

Sustainable livelihoods and the disabled extreme poor

In Bangladesh, as in many development contexts, disability and poverty are interlinked and reinforce each other. The Sustainable Livelihoods approach is a useful conceptual framework for exploring the relationship between poverty and disability and for assessing the effectiveness of income generation interventions in reducing poverty for extremely poor people.

Chambers and Conway (1992) have defined the sustainable livelihoods approach (SLA) as 'the capabilities, assets and activities required for a means of living'. They argue that it provides the basis for engaging with the complex and diverse portfolio of activities and assets people use to support themselves. This formed the basis for Department for International Development (DFID)'s adoption of the SLA in their work. The Department for International Development (DFID 2000b) conceptualise the sustainable livelihoods approach as a framework showing how access to assets are affected by the 'vulnerability context' (trends, shocks and seasonality), mediated by 'transforming structures and processes' (i.e. the policies, institutions and processes) and resulting in a number of 'livelihoods strategies' being adopted to achieve 'livelihood outcomes'.

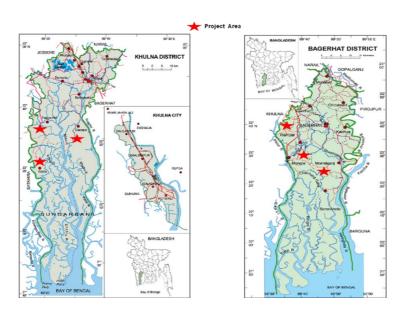
Save the Children has also adopted the sustainable livelihoods approach as a platform for the implementation of this project. The key programme area in the Household Economic and Food Security (HEFS) Project is sustainable livelihood promotion, which will help extreme poor households (including disabled people) strengthen their current livelihood options. It is hoped that diversified

livelihoods will enable them to stabilize their income during crisis periods (such as those caused by health problems or seasonally lean periods), and thus reduce household vulnerability. Similarly, by providing skills-development training, Save the Children is strengthening the capabilities of the extreme poor (including those disabled who can carry out income generating activities) and upgrading their skills, thereby opening up new avenues to earn income. The project provides extreme poor households with links to both government safety-net programmes and other NGO projects which provide education, sanitation and health services. Through this approach targeted households should improve their skills, income and social relations. In this way Save the Children intends to enhance the livelihoods of extreme poor households in the southwest coastal region, and empower them economically to become generators of sustainable income.

3. METHODS AND CONTEXT

This section outlines the methods we used in gathering information and collecting of data about extremely poor and disabled project participants. We then describe the context and background of these study participants.

Figure 1: Location of study sites



Selection of the Study Area

The six *upazilas* (sub-districts) in Khulna and Bagerhat Districts where the Household Economic and Food Security (HEFS) project is implemented are shown in Figure 1. The disability screening survey covered all households with disability within the SCI–shiree project and covered all six *upazilas* in SCI's working area. These *upazilas* were Dacope, Paikgacha and Koyra *upazilas*, from Khulna district and Mongla, Rampal and Morelganj, from Bagerhat district.

For the qualitative data collection, four *upazilas* in total (Dacope and Paikgacha from Khulna district and Rampal and Mongla from Bagerhat district) were purposively selected to give access to household heads with a variety of disabilities. The selected individuals had all received income generating assets, although some were managing their own assets, while others had established alternative livelihood arrangements with their relatives and neighbours who managed them on their behalf.

Research approach

In their baseline study, Save the Children defined disability as both physical and mental disorders. In order to calculate frequency, the baseline drew from family perceptions on disability by asking whether any household members were considered disabled regardless of age. During the disability screening survey we followed the definition provided by Bangladesh Persons with Disability Welfare Act 2001. In the qualitative data collection period we examined disability as physical or mental impairment but also examined the socio-cultural context in which negative attitudes, discrimination

and exclusion towards those with disabilities can seriously exacerbate their experience of disability.

Qualitative Methods

Three different qualitative methods were used in this study to explore the livelihood challenges of the disabled extreme poor and the complex forms of deprivation in different settings.

Life histories with disabled household heads

A total of 7 life history interviews were carried out with disabled household heads. These were all carried out over two visits for a total of four hours (2 hours in each visit). This method enabled the research team to explore respondents' lives and livelihoods and their experience of discrimination in the work place. The interviews helped researchers gain a greater insight into disabled peoples' livelihoods and the changes that resulted from the project intervention. All respondents were purposively selected to reflect a range of disabilities (speech, hearing, sight, physical, behavioral and learning) and household composition (male-headed households, female-headed households and female-managed households).

In-depth interviews with caregivers

Women (mothers or wives) are usually the primary caregivers for disabled people in Bangladesh. In this study a total of 10 caregivers (both men and women) were interviewed to learn about their experiences. In some cases it was essential to interview caregivers, as some beneficiaries had speech, hearing, learning and behavioral difficulties and were unable to respond directly themselves.

Focus group discussions

Unfortunately for this study SCI beneficiaries with disabilities were too widely scattered to allow group discussions to be organised. However Action for Disability and Development (ADD) International, an NGO that works exclusively with disabled people, operates in a similar working area to Save the Children. ADD form self-help groups with disabled beneficiaries and it was possible to conduct FGDs with these groups.

Two focus group discussions (one with men and one with women) were conducted with ADD project beneficiaries to find out how disabled people were benefitting from their village self-help group. These discussions were useful to supplement the learning derived from individual interviews with SCI beneficiaries and caregivers. A total of 20 participants (10 in each group) participated during these discussions.

Quantitative Methods

For quantitative analysis, the Save the Children baseline data collected in 2009 and 2010 were used. The team also conducted an additional disability screening survey in January-February 2012.

Baseline survey

The findings from the baseline report revealed that a total of 667 individual beneficiary household heads were considered physically or mentally disabled by other members of their household. However, in this study we have considered only disabled people who are of working age, as defined by the Government of Bangladesh (aged between 15 and 59 years). Beyond this age range, people are considered to be dependants. These definitions are used to calculate the dependency ratio (Population Census-2001, 2007). In this study 457 disabled household heads who were less than 60 years old were selected. The baseline study also provides details of the socio-economic background of disabled and extremely poor people such as their occupation, educational qualifications and access to social safety-nets.

Disability screening survey

The team conducted a disability screening survey with 357 disabled household heads in January-February 2012. The survey was designed to identify types of impairments (physical, visual, hearing, speech and psychological (both learning and behavior) disorders), causes of impairments, difficulties doing daily activities and use of assistive devices. Some questions were also asked about project interventions and access to social safety-nets. A day-long orientation workshop was organized at the *upazila* level on data collection techniques. All field facilitators including those in charge at *upazila* level from SCI's partner organizations attended the orientation workshop.

The aim for this survey was to collect data from 457 disabled household heads. However it was only possible to collect data from 357 households because 65 household heads were over 60 years old, and were therefore not included in the study; 69 household heads were not disabled (during the baseline data collection period they were identified as disabled when they were temporarily injured); 11 household heads had died; 2 had migrated and 1 withdrawn from the SCI-shiree project. 48 new household heads had become disabled since the baseline was conducted. Table 2 summarises these discrepancies between the baseline and the screening survey.

Table 2: Discrepancies in numbers between the baseline and screening surveys

Upazila	60+ (elderly)	Not disabled	Died	Migrated	Refused asset	Newly added in the list	Total
Dacope	9	20	0	0	0	9	20
Paikgacha	8	0	0	0	0	0	8
Koyra	8	0	2	0	1	1	10
Mongla	0	7	0	1	0	1	7
Rampal	20	10	1	1	0	0	32
Morrelganj	20	32	8	0	0	37	23
Total	65	69	11	2	1	48	100

Data analysis and presentation

The quantitative data from the study was analysed using Microsoft Excel and SPSS. Summary statistics from this analysis are presented below, along with findings from the qualitative life histories, individual interviews and the focus group discussions. The first section summarises background information on the disabled individuals and includes the nature and causes of the

disability, and the type of project intervention. The second focuses on challenges and problems encountered by people with disabilities, including discrimination in different settings and gaps in service delivery. The third explores different types of benefit derived from the livelihoods development project initiated by Save the Children International, including economic, social and psychological benefits.

In some cases it was not possible to collect information from a disabled participant directly because of communication problems associated with the particular disability. In these cases researchers relied on information provided by caregivers.

Background Information of disabled household heads

This section provides a demographic and background description of the disabled people who were interviewed. Relevant comparisons were also drawn with baseline data, disability screening data and qualitative findings.

Table 3: Distribution of disabled extreme poor households by districts and sex

District	Se	Sex	
	Male	Female	
Khulna	90	83	173
	(52%)	(48%)	(100%)
Bagerhat	119	65	184
	(65%)	(35%)	(100%)
Total	209	148	357
	(58.5%)	(41.5%)	(100%)

A total of 357 disabled heads of households (who were less than 60 years old) were interviewed during the disability screening survey. Out of 357, 173 (48 percent) of the households were from Khulna district and the rest were from Bagerhat. Findings indicate that disabled people in both Khulna and Bagerhat are more likely to be male.

Types of disability

The disability screening survey identified the various types of disabilities that respondents reported as hampering or reducing their ability to carry out or perform day-to-day activities. The findings, as shown in Table 4, indicate that of those who reported a disability, the majority (33 percent) were suffering from a physical impairment. Approximately 13 percent of household heads reported a visual impairment and 9.5 percent experienced hearing and speech difficulties. It was also found that 9 percent of respondents had learning difficulties. A significant proportion (about 33 percent) of people with disability reported experiencing multiple impairments. For example some individuals experienced both speech and learning difficulties or physical and mental disabilities.

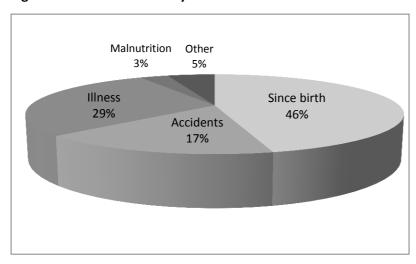
Table 4: Types of disability

Disability type	Sex		Total
	Male	Female	
Visual	30 (14.4%)	16 (10.8%)	46 (12.9%)
Hearing or speech	16 (7.7%)	18 (12.2%)	34 (9.5%)
Physical	76 (36.4%)	42 (28.4%)	118 (33.1)
Intellectual or	17 (8.1%)	15 (10.1%)	32 (9.0%)
learning			
Mental disability	10 (4.8%)	5 (3.4%)	15 (4.2%)
Multiple (More than	60 (28.7%)	52 (35.1%)	112 (31.4%)
one type)			
Total	209 (100.0%)	148	357
		(100.0%)	(100.0%)

Causes of disability

Responses on causes of disability showed that 46 percent had suffered from their impairments since birth (such as caused by an injury to their mother during pregnancy or a birth defect), 29 percent reported impairments due an illness, 17 percent due to accidents, 3 percent caused by malnutrition and 5 percent due to other external shocks or stressful social situations, such as divorce or family feuds.

Figure 2: Causes of disability



In the qualitative sample 50 percent of impairments were due to disease and illness (such as polio, *kala azar* (black fever) and high fever. The majority of these respondents mentioned that due to a lack of money their parents did not have access to proper treatment, which led to chronic disability.

Box 1 : Monica (50)

Monica (50) was blind in her right eye since birth and over time also lost vision in her left eye. Due to a lack of money her parents did not take her to a doctor.

Thirty three percent of respondents (both caregivers and disabled beneficiaries themselves), who had visual impairment, said that they have been disabled since birth. One respondent said that the cause of her son's difficulties was an injury she sustained during pregnancy.

Box 2: Fazlur (22)

According to his father, **Fazlur (22)** has had various difficulties since birth. He could not sit, talk or stand until he was 8 years old. Even now he can only call "mum" and "dad" and communicates using gestures. His disability was caused by an injury to his mother whilst she was pregnant. Just one week before giving birth his mother fell from a high place down to the ground, and was severely hurt around her waist.

Overall seventeen percent of qualitative sample had disabilities due to accidents later in life.

Assistive devices

About one third of the household heads used assistive devices to move, to do day-to-day tasks and for social and economic activities. These devices included spectacles, walking sticks, white sticks (for blind people), standing frames, wheel chairs, hearing tools, crutches and limb assistive devices. However over two-thirds of disabled household heads were not using any assistive device. Similarly the qualitative sample also revealed that many extreme poor people would have their disabilities reduced if they could have proper treatment or could afford assistive devices.

Table 5: Use of assistive devices

Using assistive device	Percentage
Yes	32.5
No	67.5
Total	100

For example Nilima's case indicates that if her parents could afford a hearing aid she could be more independent.

Box 3: Nilima Begum (30)

Nilima Begum (30) has speech and hearing difficulties. When she was child a foreign body entered her ear and she had to have a minor operation to remove it. A local doctor performed the operation but he accidently tore her eardrum. However she is unable to afford a hearing aid which would allow her to live a more independent life.

Access to social safety-net programmes

Safety-net programmes are an important component of the government's social protection strategy. However, coverage is very low among the disabled extreme poor, which is surprising given their usual levels of vulnerability. The present study findings indicate that only 31 percent of disabled household heads were receiving government safety nets meaning that a significant percent of people with disability are excluded from of government safety nets.

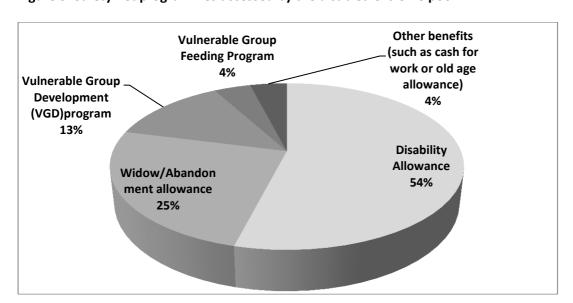


Figure 3: Safety net programmes accessed by the disabled extreme poor

It was also found that 54 percent of the disabled people who received social safety net benefits were getting disability allowances, while 25 percent were receiving widow or abandonment allowances and 20 percent are enrolled in the Vulnerable Group Development and Vulnerable Group Feeding programmes.

Occupation before intervention

Baseline data shows that out of 457 disabled household heads, 30 percent (137) were not engaged with any income generating activities before the intervention due to their disability. Another 20 percent of household heads solely relied on begging. However, 50 percent of disabled household heads were working as wage labourers (agriculture and other day labour), fishermen, transport workers (such as van pullers) and housemaids.

In the qualitative sample the working status of respondents who were engaged with income generating work before the Save the Children International intervention varied with disability. For example, respondents with physical difficulties tended to engage in small businesses while people with learning difficulties tended to work as wage labourers. We interviewed two beneficiaries with visual difficulties and found that before the intervention both of them used to beg while singing, although one also had mat weaving skills. One respondent with physical difficulties had skills to carry out tailoring.

Table 6: Occupations of the disabled extreme poor

Type of disability	Occupation	Total	
	Male	Female	
Physical	Small trade (1) Unemployed due to illness (1) Tailoring (1)	Small trade (2) Unemployed (1)	6
Visual	Singing beggar (1)	Singing beggar (1)	2
Learning	Day labourer (2)		2
Hearing and speech		Water supplier (1)	1
Multiple impairment (behavioural, learning and speech)	Unemployed (1)		1
Total	7	5	12

Educational status

The baseline data showed that about 73 percent of disabled household heads did not go to school. Although 21 percent had completed study to primary level, only 5 percent had completed junior secondary school (up to grade eight). Only 1 person completed higher secondary school (grades 9-10) and 1 person completed their Secondary School Certificate. A similar pattern was reflected in the qualitative sample. A number of sight or hearing impaired FGD participants talked about their lack of special education and mentioned that due to a lack of specially targeted medium of instruction for deaf and blind children they did not go to school.

Types of intervention from SCI-shiree project

Save the Children provided livelihood development interventions to these groups of people. According to the screening survey 291 households (over 80 percent) with a disabled household head received productive assets to establish small businesses, undertake livestock and poultry rearing, set up grocery shops, buy sewing machines and mortgage in land. A number of disabled household heads (about 50 percent) also received skill-based training for small businesses, poultry and livestock rearing and vegetable gardening. A significant number of women (101) from both female-headed and male-headed households engaged with different income generating activities after the Save the Children project intervention.

Table 7: Intervention types

Type of Intervention		Sex	
	Male	Female	
Productive asset for income generating activities (IGAs)	190	101	291
Temporary financial assistance (TFA)	19	47	66
Total	209	148	357

About 19 percent of disabled household heads were only receiving temporary financial assistance (TFA) because they lacked the ability to adopt any livelihood-based option.

IGA operator

The disability screening survey data showed that 40 percent of disabled household heads were maintaining and operating Save the Children International-provided assets independently, while 60 percent of disabled households were taking care of their assets and livelihoods with the support of family members or relatives.

4. LIVELIHOOD CHALLENGES EXPERIENCED BY PEOPLE WITH DISABILITY

Disabled study participants faced significant challenges in maintaining income-generating activities. Individual interview and focus group participants reported that the situation was worse in rural areas compared with urban areas because of more limited work opportunities, poorer education and health care facilities, and higher levels of discrimination. Table 8 below summarizes the challenges faced in generating income as reported by these disabled people, both for those who can manage their assets themselves and for those who relied on others.

Table 8: Challenges face by disabled beneficiaries in generating income

Income generation arrangement	Challenges
Self-operated income generating activity	 Inability to do physical work for long periods
	 The need to rely on others which increased labour costs
	 Lack of assistive devices
	 Lack of appropriate income generation capital or equipment
	 Difficulties travelling to work
Income generation with management supported by family or relatives	 Difficulties selecting appropriate supporter and IGA
	 Inadequate support from support provider
	 Lack of formal savings plan for the disabled person
	 Old age of caregiver (for example when they were parents)
Challenges common to both arrangements	 Lack of employment opportunities or lower wages due to discrimination
	 Lack of access to health services or inadequate quality of health services
	 Vulnerability to natural disasters
	 Social and cultural exclusion, stigma and marginalization

Inability to undertake physical work for long periods of time

Box 4: Zishan and Babar

Zishan (34) has a hunched back and gradually his legs are thinning. From the SC-shiree project he received a sewing machine and unstitched cloth for business. With the help of his wife he is getting a good amount of money from his tailoring and cloth business. However, he cannot continue his work for a long time due to his physical difficulties and having to take regular medicine.

Similarly, **Babar** who had spinal cord injury cannot sit for a long time in his snack shop as it makes him weak.

Both interviews and focus group discussions revealed that the most common limitation for disabled people in generating income was their inability to do physical work for long periods of time.

Despite these difficulties, disabled extreme poor people were still keen to work because not working was likely to lead to social isolation and financial difficulties. Both Komola and Abida (below) shared why they had to engage with income generating activities.

Box 5: Komola and Abida

Komola is a paraplegic and her husband left her. She arranged her daughter's marriage to a day labourer, but they are unable to support her and live separately. To survive Komola runs a firewood business.

Abida Begum (30) has mobility difficulties. Despite her physical problems she is the breadwinner of her family, because her husband has been suffering from paralysis for the last six years and has been totally bedridden for the last two years.

Difficulties travelling to work

Three respondents from the life history interviews reported facing difficulties when travelling to work. Most said they had to rely on public transport or the help of family members and relatives. Sometimes they had greater difficulties during the monsoon and had to wait for longer times.

Box 6: Babar and Abida

Babar set up a snack shop in a town 3 kilometers away from his house. Due to his spinal cord injury and thinning leg he cannot walk with heavy loads. Therefore his wife has to carry food and other goods to the main road from where he can hire a rickshaw van.

Abida also has problem with mobility and has to use transportation outside of the home to get around. She has to use a rickshaw van to go to her shop business which is about 2 kilometers away from her home.

Wage Discrimination against people with disabilities

A number of respondents from the individual interviews and focus group discussions shared their experiences of wage discrimination within the workplace. Most of them were only able to do manual work as they had no formal education.

Box 7: Zishan

Zishan has a hunched back. It was difficult for him to get a different job as people did not want to hire him as a day labourer due to his physical disability. He said "I therefore found work in a tailoring shop but used to get paid less than other staff members. Sometimes I had to work for a day and the owner used to pay only 10 taka whereas other workers got 60 to 70 taka. I also worked as guard at a shrimp enclosure and earned only 20 taka per night where non-disabled workers received 100 to 150 taka".

Most respondents said that due to their physical impairments employers were reluctant to hire them. Kasem (Box 8 below) described how before the SCI intervention he was discriminated against in the workplace.

Box 8: Kasem and Rehka

Kasem has learning and speech difficulties and works as a wage labourer. He cannot calculate well and people cheat him frequently. His wife explained that even when he works for a full day he only gets paid 500 grams of rice which is worth about 12-14 taka (this is compared to 150-200 taka for non-disabled workers). In addition, sometimes shopkeepers also charge him a higher price as they know he cannot count very well (e.g. He paid 30 taka for 1 kilogram rice instead of 25 taka).

Rekha has both learning and physical difficulties. She supplies water to the tea stalls and earns 1 taka for a pitcher of water where other people get 4-5 taka for the same work.

Individual interviews and FGD findings showed that those with learning difficulties in particular were engaged in various farm and non-farm (earth digging, water supply) labour on a daily basis. A number of respondents reported that in these roles they were paid less than the going rate for this work. This happened in the cases of Hasem, Mofizul Molla and Shikha.

Box 9: Rina

Rina has a visual impairment with her one eye. She is now studying a Bachelor of Arts degree under National University and working as private tutor. She explained that "I have to teach for a longer time and the guardians pay me less money compared to other teachers".

FGD participants also shared that even if they had qualifications to higher secondary or bachelor of commerce degree levels, they still suffered the same discrimination in the workplace. This suggests that it is not only less educated disabled people who discriminated against in the workplace but educated disabled people also.

Exclusion from employment in government

Box 10: Monjita

Monjita said that she had qualified in a written test 8 to 10 times in primary school teaching interviews. However whenever she faced a viva board the examiner or board members only asked her name and did not recruit her.

One FGD participant said that she qualified in a written test 8 to 10 times in primary school teaching interviews, but they did not recruit her for the job. She believed that it was due to her physical impairment (she has physical problems in her leg and walks with a limp) that they did not recruit her for the job.

Lack of access to health care services and low quality of services

Box 11: Abida

Abida went to the upazila health complex but the doctor did not listen to her and gave her a prescription for medication which did not work. A week later she visited the same doctor's private chamber where he charged 160 taka per visit. Only then did the doctor spend 30 mins to talk and listen to her.

Three respondents from the life history interviews mentioned that when they went to the government hospital but did not get proper care. Abida had an accident and because she didn't receive proper treatment she became permanently disabled. She explained how poorer people are less able to access quality health even at government health care centres and because of this they are more likely to suffer permanent, yet preventable, disability due to poor treatment. This also happened to Nilima. Due to mistaken treatment she now cannot hear and speak clearly.

Box 12: Rashid and Abida

Rashid (50 years) has been suffering from paralysis for the last 9 years. He had his first stroke in 2003 and a second in 2008. In February 2012 Shahid suffered another stroke. At that time Zamila (Shahid's wife) had 14000 taka from their crab business and she had to spend 10000 taka for her husband's treatment.

Similarly due to accident **Abida** lost her working days and had to spend about 3 to 4 thousand taka. She had to purchase food items on credit from a shopkeeper. She also purchased some medicines on credit from a pharmacy.

The qualitative interviews showed that ill health associated disabled people's disability could quickly erode income and assets, further exacerbating their vulnerability. Working days were often lost due to illnesses and working capital was used to purchase food, medicines or to pay for credit.

Natural disasters damaging disabled peoples' assets and livelihoods

The southwest coastal region is extremely vulnerable to natural and climate change-related disaster. People in this area are vulnerable to cyclones, tidal surges, river erosion and salinized water and soil. Extremely poor people tend to suffer disproportionately because they tend to live in more exposed places and depend on natural and common property resources for survival. Within the extreme poor group the disabled are still more vulnerable as they tend to be physically weaker, have weaker social networks, and are least likely to be resilient when disaster strikes. For example one respondent named Rashid lost his working capital during the tidal surge of 2010 and it has had a long-term detrimental impact on his family.

Box 13: Zamila

The Save the Children-Shiree project provided 8000 taka to Zamila (Shahid's wife) for a crab fattening business in their small pond. Unfortunately in October 2010 a tidal storm washed away all of their crabs, worth around 6000 taka.

Social and cultural challenges

People with disability not only faced economic challenges but also experienced a variety of forms of social or cultural exclusion, discrimination or stigmatization. Parental disability also had negative effects on children's lives.

Gender dimensions of disability

Gender inequality is deeply embedded in the overall social structure in Bangladesh. In this patriarchal setting women are deprived in most spheres of their lives. Social customs and traditions, high illiteracy rates and poor employment opportunities have hampered the integration of women into mainstream of development activities. In this study we observed that poverty affected men and women project beneficiaries in different ways, since their social roles were different. Disabled women tended to be the most disadvantaged group among the extreme poor. Several other studies have also showed that women with disabilities suffer a double discrimination, both on the grounds of their gender and their impairment (DFID, 2000).

Women with disabilities

Box 14: Mina

Mina has difficulties with her right hand and leg. Despite her disability her elder brother arranged Mina's marriage to a poor man by promising to give him 33 decimals (1/3 of an acre) of land. The poor man got married to Mina, but her brother did not keep his promise. As a result both her mother–in-law and her husband tortured her in an attempt to get the land. When this did not work after 7 months, her husband divorced her. Mina said: "He didn't marry me, he married the land. If he had married me, he would not have left me".

Most marriages of female respondents with disabilities took place with unusually large dowries of cash, other assets, or land. In addition when these women became ill or more disabled they were also more likely to be abandoned or separated. Thus disability seems to exacerbate the existing discrimination and vulnerability women in Bangladesh suffer in marriage and dowry arrangements.

Some women with disabilities felt that they were being used only as childbearing machines. The following case of Komola shows that although she had a physical problem, she was chosen as a wife for her childbearing abilities.

Box 15: Komola

Komola is paraplegic. Her husband's first wife arranged for Komola to marry her husband because she had an infertility problem and as a result he was trying to get married to another woman. According to Komola, despite her disability, her husband's first wife chose her. This was because she knew if her husband get married to a non-disabled person, he may leave her altogether (susthan meyeke bie korleto she bhat pabena, amake neleto amake marleo kitchu korte parbona). Three years after her marriage she gave birth to her first boy. Unfortunately her boy suffered from pneumonia and died within a month. The following year her husband's first wife also gave birth to a baby boy. One year later Komola gave birth to a baby girl. A few years later, when Komola was visiting her father's house with her daughter, who was only 3 years old, her husband along with his first wife and son moved to India and left her behind.

Women living with disabled husbands

Extremely poor women were also more likely to end up in disabled households, even if they are not disabled themselves. This occurred because extremely poor families are often unable to afford a large dowry. A small dowry often leads to girls being married to disabled or elderly men. This problem appears to be more severe in cases where the female is getting married for the second time. It was also found that when women have disabled husbands, they are often disrespected, stigmatized and deprived in many ways.

Conversely when males are sick or disabled, it has been found that their wives commonly work hard to provide for the whole family and do not leave their husbands.

Box 16: Amena

Amena's family could not meet the dowry demands for her first marriage. Her husband and his mother used to torture her and eventually he divorced her. Amena's second marriage was to a mentally disabled man named Akash as no other arrangements could be made. With the support of SCI, Amena is now a tailor and runs a small business. However she has to sell clothes on credit, and customers do not pay in due time, because they know she has no one to protest or to claim the due amounts on her behalf. Her husband's family members have also recently deprived them from land inheritance as they divided the property between her husband's two brothers. Amena and Akash were not even informed when the land was sold.

Box 17: Rashid

Rashid has been suffering from paralysis for the last nine years. His wife was 36 years old when he became ill. She would never think to get remarried as she could not leave her husband. She has been taking care of him and their children ever since.

Negative attitudes towards people with disabilities

Box 18: Komola

Komola shared that people did do not want to eat from her hand (as she has to crawl on her arm to move around) and this had made her very sad. The people in her community say of her "char hat pa die hate" (She has four legs).

A number of disabled respondents from the FGDs and individual interviews reported that they had experienced a range of exclusionary attitudes in their daily life with in particular verbal attacks, jokes and bullying. The majority of respondents shared that the most common form of bullying experienced was verbal (name calling, insulting and teasing (e.g. "bent Zishan", "limpy", "crazy"), followed by emotional torment (e.g. laughing at them) and physical abuse (e.g. throwing things). This was frequently done by children but also by older neighbours. Both FGD participants and respondents from individual interviews mentioned that people who had hearing difficulties, also suffer abuse and people call them *kala* ("*kala*" is a derogatory term for people with hearing impairments).

The most common name calling for people with mentally ill or learning difficulties was the term *pagol* (a derogatory term meaning "mad" or "crazy"). They also reported experiencing both verbal and physical abuse.

Box 19: Amena

Amena (Kashem's wife) shared that both their family members and other community people call her husband "pagol" and call her pagoler bou (wife of crazy person). Her husband often experiences both verbal and physical attacks (people throwing things at him).

The impact of disability on children

Parental disability forces children into work at a young age, and they are also likely to experience exploitation, bullying and social exclusion. One respondent from a life history interview reported that she had to stop her children's schooling and force them to work.

Box 20: Rashid

When **Rashid** had a stroke for the first time his wife fully engaged herself in caring her husband. But she was not able to cover the cost of his medicine or provide food for the family. They therefore relied on their eldest son, who was only 12 years old, to earn money for the family by pulling a rickshaw van. To do this the boy had to stop his schooling. In April 2012 Rashid had a third stroke, and they had to spend their business capital that had been provided by Save the Children International. As a result his youngest son was also forced into pulling a rickshaw van.

Also, due to parental disability, children experienced bullying at school and from neighbours or children who lived nearby. One respondent from individual interview shared her experience of how she had to face difficulties during and after her daughter's marriage.

Box 21: Mofizur, Zishan and Komola

During the field work we observed neighbours calling **Mofizur**'s daughter "pagoler meye" (daughter of mad person).

Zishan also said that sometimes his daughter comes home from school very upset and cries because they call her beka Zishaner meye (daughter of bent Zishan).

As noted earlier **Komola** is a paraplegic and during her daughter's marriage she had to face some social restriction. When the wedding was arranged, some members of her son-in-laws side did not agree to the marriage. This was despite the fact that Komola's daughter studied up to class eight whilst her husband-to-be did not go to school. Komola says that ("khurar meye tai atta choto kore thakte hoi) due to her physical problem her daughter cannot raise her voice within her house and has to suffer verbal abuse from her in-laws.

5. BENEFITS FROM INCOME GENERATION INTERVENTIONS

In this section we provide an overview of the benefits derived from the various income-generating activities and other project interventions. This section draws heavily from information from the life history interviews, caregiver interviews and focus group discussions.

Material and livelihood benefits

Findings from the individual interviews demonstrate that a significant number of households gained economic benefit from income generating activities in various ways. These include strengthening their small businesses, diversifying sources of income, accumulation of productive and non-

productive assets and accumulating money for regular meals, medical expenses, and reinvestment in other IGAs, house repairs and construction of raised plinths of households as protection against flooding.

We found that very small businesses (such as betel leaf and nut businesses, cloth businesses, snack businesses) were viable livelihoods options for people with disabilities. These required minimal physical effort and mobility and allowed disabled people to earn a regular income. Most of the respondents were able to run shops, cloth or firewood businesses from their home.

Those with visual impairments did better with handicrafts such as mat weaving. These activities benefit from technical and vocational training on different items to increase skills.

People with psychological disorders, behavioral problems and learning difficulties were more likely to be involved with unskilled work such as day labouring. At the same time these people had to face a range of exclusionary attitude in their daily life. These individuals need more protection and support that will enhance their ability to cope and to give them a sense of self-worth and belonging. Families and communities also need awareness raising on psychosocial care and support to reduce discrimination and stigmatization and improve positive caring.

The following are some details on how Save the Children interventions transformed livelihoods.

Strengthened businesses

Disabled household heads who continued pre-existing activities expressed very positive views about project interventions. Three respondents from the life-history interviews stated that after receiving support from the SCI-shiree project they were able to undertake income-generating activities more efficiently and on a wider scale. Many disabled household heads engaged in small business before joining SCI reported difficulties in running their businesses smoothly due to lack of capital. However after the intervention they were able to consolidate their business and increase profits.

Box 22: Babar Ali

Babar Ali had worked as a wage labourer. Three and a half years ago he had an accident when he was lifting a heavy load and injured his spinal cord. Although he got better he never fully recovered and could not return to day labour. One year later he borrowed 2000 taka from his relative and started a snack business (selling nuts, various types of peas and chickpeas). However he was unable to earn a sufficient profit due to his lack of capital.

In September 2010, **Babar Ali** received 10,000 taka from Save the Children International to strengthen his snack business,s and 3000 taka for poultry rearing. We observed that within 2 years of the SCI intervention he had started profiting significantly from his roadside snack shop. He had set up his shop in front of the Union Parishad complex on public land and did not need to pay rent. During the weekly hat (market) he was earning 900 to 1000 taka and on normal days he earned 700 taka. This was giving him an average profit of 200 to 250 taka per day. Previously he could only purchase a small quantity of food items, but now with working capital of about 16000 taka he can afford to buy 50 kgs of nut, 114 kgs of chola, and various types of peas and firewood at one time.

Re-investing money in existing businesses

Due to asset transfer and capacity building, a number of disabled household heads are now engaged in enterprises that help them to earn for their family. Moreover, with the profit of their businesses some have re-invested to expand existing enterprises.

Box 23: Monica

Despite **Monica's** visual impairment, when she was 10 years old she learned mat weaving using *hogla* leaves. On December 2010 Save the Children International provided 4700 taka for Monica to buy raw materials (*hogla* leaves) for mat weaving. This was followed in September 2011 where SCI provided a further 4000 taka of support. With the profit from her mat making and second round of support she leased out a *hogla* garden for 8000 thousand taka for a year. Now she is able to store dry *hogla* leaves worth 8000 taka that can be used for the next six months.

Diversifying income sources

Just under half of respondent household heads were earning income from multiple sources and had increased household income as a result. For example from initial support in starting a tailoring business, Zishan (Box 24) was able to cumulatively expand into other small enterprises and increase his income and quality of life.

Box 24: Zishan

On March 2011, **Zishan** received support in the form of a sewing machine (6425 taka) and unstitched cloth (7000 taka) to start a new business. He also received small business training and vegetable gardening training. Before the intervention Zishan attended Sonali Tailoring Mobile College for tailoring training for which he paid 500 taka. He was then able to train his wife based on what he had learnt. Now with the help of his wife, he is earning an average of 100 taka profit per day from his tailoring business. With the profit of his business he bought a carrom board (a board game) which he is renting out within the community for 35 to 40 taka per day. He invested some money to buy some dry food items (cake, biscuits, crisps) to sell in his shop and bought a second hand sewing machine for 2200 taka for making different sized bags. He has also been able to invest some of the profit to improve his quality life (e.g. he bought a ceiling fan and a mobile phone).

A number of respondents also explained that after 2 years of project intervention they had bought productive assets such as rickshaw vans, livestock or poultry. It was also common to be able to buy other daily necessities, new clothes and small luxuries.

Protecting households through plinth raising and repairs

Box 25: Babar and Fazlur

In May 2012 **Babar** spent 9000 taka for plinth raising to protect his house from flood water/rainwater. Similarly **Fazlur's** father also repaired his house spending about 6000 taka.

After the SCI intervention, a number of households (33 percent) invested money for plinth raising and repairing their house. The coastal region in which SCI implements this project is characterized by frequent natural disasters. Households are therefore keen to build physical protection against flooding and secure their homestead and assets where possible.

Increased purchasing capacity

Most of respondents and caregivers expressed a positive view that the livelihoods support had increased their purchasing capacity.

Box 26: Komola and Babar

With the aid of SCI **Komola** initiated a firewood business with 3900 taka. Within 2 years of SCI intervention, at her working capital was 10,000. With profit from the firewood business, she bought a television (3000 taka), a mobile phone (2000 taka) and some silver jewelry items for her daughter and granddaughter. Her income also enabled her to pay back the loan that she took to pay for her daughter's marriage.

With the profit from his business **Babar** bought a house for 16000 taka with a loan from his elder brother. Although so far he has only paid back 8000 taka he is confident that he will be able to pay the rest of the loan gradually. His wife also bought some new sarees and clothes for their children. **Amena (Kashem's** wife) bought a cot/bed for 800 taka and a second hand mobile phone for 1000

Increased ability to afford children's education costs

The majority of the SCI beneficiaries had not finished to school. However most respondents from the life-history interviews recognized the value of education and indicated that they intended to send their children to government primary or NGO schools. Thus it seems that the SCI intervention is benefitting not only disabled people but also their children and other family members.

Increased affordability of medicine

Box 27: Zishan

Zishan previously had great difficulty paying for his medicine cost (7.50 taka for per vitamin tablet) but now can easily afford to do so.

The majority of respondents reported improvements in their ability to afford essential medicines.

Social benefits

A number of respondents shared that this project intervention not only benefitted them economically, but after getting involved with income generating activities and skills training their social status also improved.

Box 28: Komola

Komola said that before the intervention she was not able to invite her daughter and son-in-law to her house. Now sometimes she invites them over and can arrange a meal for them. She has also developed a good relationship with her daughter-in-laws family. Previously her daughter-in-law did not invite her to their house but now they often invite her over for food. She now has the ability to lend money to her relatives (during her brother's funeral, she lent 2000 taka to her brother's wife). She has also developed a good relationship with wood suppliers and sometimes purchases firewood on credit.

Komola is one example, while Zishan developed a good relationship with his in-laws, which he thinks is a result of the SCI intervention. One respondent also shared that before their involvement with

SC-Shiree they could not afford to attend any events they were invited to. Now however they attend all events and are able to spend a minimum of 200 taka for gift when she is attending the event.

Box 29: Abida

When **Abida** was ill she had to stop her business for two weeks. However during this time she was able to purchase food items on credit. She also purchased some medicines on credit from a pharmacy.

One respondent mentioned that before initiating her betel leaf business she did not know other traders in the local market. Now she has to come every day to the local market and so has got to know the traders and has developed a good relationship with them. She also has the ability to pay their credit back.

The findings provide strong evidence of the positive change to quality of life in the last two years. The disabled beneficiaries are now respected by family members, relatives, and the community. They have also been able to develop a strong business relationship with traders. These developments have increased their social acceptance and dignity.

Self-help groups of disabled people

Box 30: Juthi

Juthi has speech difficulties. She fell into trouble when a man kidnapped her from the area but when the group members found out they communicated with each other over mobile phone and rescued her.

One male participant commented that "Nobody will value me if I go alone to claim our rights. But they will care if we raise our voice jointly".

Both Male and female FGD participants reported that through self-help groups they took part in various social services. Before this they had been scattered, and had not known each other. The members of the self-help group said that because of this they had felt that nobody had cared for them, but now they had forged links with each other and established solid relationships. They were able to communicate with each other with mobile phones and said that they felt their social acceptance had increased.

A clear example of this comes from the experience of one of the group member who has speech difficulties. With their strength as a group they took part in their member's family conflicts and helped him to claim their rights and entitlement. Such examples show that the self-help group has played an active role in providing care for other disabled individuals by facilitating the development of strong relationships and a solid network among the group members.

Psychological benefits

A number of interview respondents and FGD participants reported the psychological changes they had experiences as a result of the intervention.

Most of FGD participant agreed that after being involved with the self-help group they become confident enough to claim their rights and entitlements. They also shared their experiences and observations which gave them a sense of group solidarity.

During his life history interview, Babar expressed that after his accident, he had low self-esteem because he had to stay in bed and could not work. He also had to sell all his homestead land, his wife's share of her natal home, and her jewelry to pay for treatment. After his partial recovery from his spinal cord injury he started his snack business on a small scale. The SCI intervention helped him to expand his business and as a result he was able to purchase a house from his elder brother for 16000 taka. With the help of his wife he is running his business smoothly and his confidence has increased.

Babar's wife also mentioned that before her husband's illness she was confined at home. She had little mobility, but now she goes to the *upazila* health complex and the local market. She said that she was helping her husband, had greater confidence and is better able to manage her family and afford better food for her children.

Komola also reported a number of positive outcomes, presented for clarity in Table 9 below.

Table 9: Changes due to income generation (Komola's case)

General categories of change	Particular indicators of change
Increased material resources	She has regular income from her firewood business
	 She has purchased a television for 3000 taka and a mobile phone for 2000 taka
	 The quality of food she eats has improved and she can now afford to eat fish and vegetables regularly
	 She bought some items of jewelry for her granddaughters
	 She saves 50 taka per week in a cooperative group (samiti) in the local bazaar
Enhanced social resources	Increased social status
	She can lend money to her relatives
	She can invite her son-in-law for dinner
	She can buy presents for her grand daughters
Increased confidence and mental satisfaction	 Now she is happy and feels confident to run her business. She has developed a business strategy.

Alternative arrangements for people with severe disabilities

As mentioned earlier, the project focused on addressing the current need for food and cash through linkages with safety net programmes or through Temporary Financial Assistance (TFA). In addition Save the Children made linkage arrangements for TFA recipients who were unable to operate their own livelihood activities due to severe disability.

Box 31: Amena and Kashem

Amena shared that her husband, Kashem, has learning difficulties. He works as a day labourer. SCI provided a fish net for Kashem in July 2010 and five months later she received support for a tailoring business. Before the intervention they had to stay in her husband's cousin's balcony. She owned an old sewing machine which she got from her father and was able to earn good money from her tailoring and cloth business. From one saree she could make 100 to 400 taka profit. With the profit from her business she built a small house (wall and roof made of nypa leaves), she also bought a small bed for 800 taka. Within 2 years of the intervention she had saved 7000 taka and bought 5 poultry birds for 1000 taka. She also bought a second hand mobile phone for 1000 taka. From the poultry bird she sold eggs which helped her afford nutritious food for her young daughter who is only 1 and ½ years old.

In this study we had 7 interviews with people with a disability who were unable to engage with income generating activities. Save the Children made alternative arrangements for these people with family members and relatives. Data from the individual interviews revealed that family members (parents, wife and sister) played a major role in caring for individuals with a disability in this study area. The majority of caregivers agreed that due to livelihood support they had benefitted in various ways.

For example a land mortgage arrangement for crop cultivation secured Mina's (Box 32 below) regular food and the alternative arrangement benefitted her whole family.

Box 32: Mina Roy

Mina Roy (40) is a disabled woman and divorcee and lives alone in her brother's land. She is physically unable do hard work and had to depend on disability allowance (300 taka per month). Before the intervention sometimes her elder sister used to provide food items to her but these were not adequate. She received temporary financial assistance (300 taka per month) from the beginning of the project in 2010. SC made linkage arrangement with her elder sister in 2011 and mortgaged 15 decimals of cultivable land for her with 10,000 taka. However this was on the condition that she would bear Mina's food, treatment and all expenses for the rest of her life. Now her elder sister is providing 15 to 20 kgs of rice per month, and buying vegetables and medicine for her. Mina said that, before the intervention she worried about finding food, but now she has no tension for food and treatment cost. She also added that before the intervention her elder sister used to provide support, but not on regular basis. Now however her sister is providing support on a regular basis.

Fazlur's father was also one of those who shared this experience.

Box 33: Fazlur

Fazlur (22) has had various difficulties since birth and still needs constant supervision from his parents. Both his mother and father are taking care of him. The SCI-shiree project provided two goats (April 2010) and one net for his father (December 2010). This helped the family greatly and now they can provide regular food for Fazlur. Sometimes he suffers from fever and other problems, but previously his parents were unable to afford the treatment cost. The whole of Fazlur's family have benefited from this support. With the profit from the fish selling his father purchased a cow for 10,000 taka. Over the past two years their assets increased (from 2 goats to 8 goats). Fazlur's father also repaired his house spending about 6000 taka.

However findings also revealed that some alternative arrangements such as livestock rearing and seasonal (half yearly) interest from land lease agreement did not bring immediate and adequate income for that household.

Box 34: Mofizur Mollah

Mofizur Mollah has learning difficulties. He is also suffering from piles and dysentery. According to Mofizur Mollah's mother, both Mofizur and his wife have learning difficulties. She referred to them as "pagol" (i.e. having some form of psychological disorder or severe learning disability). One of his sons also has similar symptoms and cannot recall school lessons. Project staff tried to find a reliable person to take care of Mofizur's asset but both of his parents are now elderly. Mofizur, with consultation with his mother chose his uncle (Mofizur's father's cousin) to help manage the asset. His uncle has 500 decimals of land, so project staff made an agreement with his uncle for 8 decimals of mortgaged land and it was decided that his uncle would provide 4000 taka yearly as interest. However this money was not immediately available and income needed to be generated from elsewhere. Mofizur is physically very weak and cannot work hard, so most of the time he goes to beg. His wife works as a day labourer in a shrimp enclosure and sometimes she also has to beg to maintain their family.

The above case illustrates the problem of not having adequate income for daily needs and even though an asset was transferred in the form of four thousand taka per year, paid in two installments.

The above cases demonstrate how people with disabilities and their family members are capable of enhancing self-employment and creating livelihood options after getting support and opportunities from Save the Children HEFS project. In spite of Mofizul Mollah's case, overall these findings show that involvement with income generating activities, or the productive use of an asset, provided disabled people and their families the opportunity to improve their higher incomes, enhance their dignity and strengthen their ability to cope with crises or shocks.

6. CONCLUSIONS AND RECOMMENDATIONS:

It is clear that disabled people are the most vulnerable and disadvantaged group in Save the Children's working area. Disabled people face significant challenges in maintaining their livelihood activities. The most common limitation is an inability do physical work over long periods due to physical impairments, which results in prospective employers not wanting to recruit or hire them. A number of respondents who had physical and mental disabilities experienced wage discrimination within the workplace. They are therefore deprived of employment opportunities and deprived of a fair wage.

It was found that in particular those who have visual, speech and hearing difficulties are deprived of special education and other opportunities. As disabled people are not getting access to proper education, they are unable to get skilled jobs, driving them further into poverty.

Findings also revealed that the ill health associated with their impairments often further erodes their income and assets, as they lose working days and have to spend money on treatment. Sometimes they are even forced to sell assets to pay for treatment costs.

Disabled people are subjected to various types of discrimination and negative attitudes in their daily lives. In particular women with disabilities experience double discrimination. Respondents reported exclusionary and discriminatory attitudes displayed in verbal attacks, jokes or bullying. They reported exclusion from land inheritance. Children are also affected by the negative attitudes and

behavior of family members and wider society, often through bullying, which leads to self low esteem. Thus discrimination, social exclusion and isolation are a frequent part of life, for both the disabled person and their family. They are often neglected by their families, neighbours and community.

On a positive note however it is important to highlight that disability did not prevent the respondents from striving to be independent and contributing towards improving their families. Komola, Zishan, Babar, Abida and Monica all benefitted from the project intervention, as it enabled them to achieve greater livelihood security, equality and inclusion in society. The majority of respondents stated that they gained economic benefits from income generating activities in various ways. These included strengthening small businesses, diversifying sources of income, accumulating productive and non-productive assets, raising money for regular meals and medical expenses, and reinvesting in other IGAs, house repairs and the construction of raised plinths of households as protection against flooding.

Alternative arrangements with family members and relatives benefitted both people with severe disabilities and their family members and relatives. The self-help groups also showed how people with disabilities have been able organize to claim their rights and entitlements.

Inclusion into income generating activities and skill development are two important ways of supporting extremely poor disabled people and reducing their vulnerabilities. The involvement with income generating activities or the productive use of an asset provided disabled people the opportunity to improve their incomes and social dignity, and allowed them to strengthen their ability to cope with crises or shocks in a sustainable way.

RECOMMENDATIONS

A range of specific issues emerge from this study which urgently need to be addressed in order that extremely poor disabled people are adequately supported in income generation and protected from discrimination as they work to improve their lives. The following provide a summary of some important programme-level and policy-level recommendations that emerge from this study.

Programme-level recommendations

- Hold more one-on-one follow up sessions with disabled beneficiary households to build motivation and encouragement to maintain their IGAs
- Select appropriate IGAs which will bring immediate, regular and adequate income for households. For example, tailoring and chopping wood were difficult for people with physically impairments. It was also found that livestock rearing and seasonal (half yearly) interest from land lease agreements did not bring immediate and adequate income for households.
- Ensure savings plans to secure the future of disabled people.
- Develop a clear agreement with an outline of supporter responsibilities and asset ownership in cases where supporters help to manage assets (e.g. supporter responsible to provide food (how much per week or month) and costs for medical treatment).
- Establish networks with disabled people's organizations to ensure community based rehabilitation, and better access to assistive devices. Community based rehabilitation can also improve skills and attitudes, support on the job training and provide guidance to employers.

- Help participants to engage with disabled self-help groups to claim rights and entitlements (make a list of disability rights organizations. Where to go to and where to get information can be shared in courtyard sessions.
- Explore ways of engaging with vocational training institutes. Map availability of common vocational training initiatives in Khulna and Bagerhat districts and their accessibility for disabled people.
- Promote awareness through courtyard sessions to reduce stigma and discrimination of disabled people. These could promote within-family caring for disabled people since the best people to provide psychosocial support are families and communities.
- Most people with disability experienced various types of stigma and discrimination within families and communities and so social programmes aimed at reducing discrimination and abuse are needed.

Policy-level recommendations

- Greater attention to the inadequacy of government safety-nets for people with disability
 and advocacy with local government institutions to increase access to social protection and
 safety-net scheme. Community level support needs to be backed by the external efforts of
 policy-makers. This includes strengthening social protection and rehabilitation services and
 better observance of laws on dowry, inheritance and disability rights.
- Improvement of health care services at the rural level for extremely poor disabled people.
- Disabled persons have difficulties with transport and there is a lack of disabled-friendly infrastructure (such as roads and pavements, health complexes, schools and cyclone shelters). Therefore, government departments should pursue a more disabled friendly infrastructure.
- Disabled children, in particular those who have visual, speech and hearing difficulties tend to be excluded in education. Policy makers need to address disabled children's barriers to education. For those with physical impairments it is difficult to reach distant schools using inaccessible village roads.

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ANNEX: DISABILITY SCREENING SURVEY FORMAT

Save the Children
Disability Screening Form
Individual's disability related information

Profile

Date of screening:	ID No/Form No	
Name of the informant/Respondent:	Relation with the disable person (If disable	
	person is unable to give	information):
Name of the disabled HHH:	Age:	Sex:
Father/Husband/Wife's Name:	Total member of the Household:	
Address: Village/Para:	Union/Ward's Name:	
Upazilla/Pawrashava	District:	Mobile (If have):

Disability Screening/Identification

The person.....(Please Mark Tick)

Unable to see distant objects (1)	Display inattention/restlessness (4)	
Inflamed or watery eyes (1)	Difficulties in learning, understand and	
	remember (4)	
Blurred/Unclear or double vision (1)	Difficulties in activity of daily living compare to	
	others (4)	
Difficulty in hearing (2)	Behavior problem(strange manner) (5)	
Speech difficulty (2)	Tendency of over suspicion (5)	
Difficulty in walking/movement independently	Restless/ show repetitive behavior/ hurt own-	
(3)	self/ difficulty to communicate properly (6)	
Difficulty in catching/lifting objects (3)	Person/children having two or more types of	
	difficulties e.g.(4) intellectual and (3) physical =	
	(7)	
Deformity/ contracture (3)	Other specific problem/limitation/symptom	

Types of Disabilities

Visual impairment ()	Hearing	and/	Speech	Physical Impairment ()
	Impairmen	ıt ()		
Intellectual disability ()	5. Mental o	disability()		6. Autism Spectrum Disorder()
7. Multiple disabilities				

Performing daily living activities

<u> </u>						
Alone ()	Need some Assistant (Need	Moderate	Full Assistance ()		
)	Assistant ()			
If can't perform, Who assists: Mother (), Father (), Sister/Brother (), Husband/Wife (), Grand						
Father/Mother Son/Daughter (), Others (), None ().						
Probable Cause of Disability: Born with (), During birth (), After birth (), Illness (), Malnutrition (),						
Accident: At work (), traffic (), home (); Unknown (), Others ()						
Does the person need any assistive device: Yes (), No ().						

Types of devices: Wheelchair, Cycle, Tricycle, Walking stick, Toilet chair, Standing frame, Specialized chair, Crutch, Artificial limb, white cane, spectacular, hearing aid, Others.......

Involvement with the project

Date of inclusion with HEFS project				
What types of support are you getting from the project? (1) Temporary financial assistance (2) IGAs				
If TFA, how much do you get?	(1) 300 taka/month	(2) 600 taka/month		

What types of training have you got? (1) Skill transfer (2) Awareness (3) Both 1&2 (4) No training						
What types of IGAs have you got (Name) ?						
Who operates the IGAs (relation)?						
What kind of changes have made of this household by this IGAs?						
Economic	2) Social	3)Emotional	4) Others			
Have you got access to government safety net?		(1) Yes		(2) No		
Types of Safety	net; 1) Disa	ability allowance	2) VGD	3) VGF	4) Old age allowance	5)
Others						

Name, Designation and Signature of the data collector

Name of the verifier:

Note:

The age of the disabled person should be within the range of 15 to 59 years.

People who are 60+ years old and having disability, would not be considered in this survey.

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