



Knowledge and Experiences of Disability in Rural and Urban Areas of Bangladesh: A Qualitative Study

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Acronyms and Abbreviations

ABC	Assistance for Blind Children
BVIPS	Bangladesh Visually Impaired People's Society
CDD	Centre for Disability in Development
DCC	Dhaka City Corporation
DPO	Disabled Peoples Organisations
FGD	Focus Group Discussions
GoB	Government of Bangladesh
IDI	In-depth Interview
JPUF	Jatiyo Protibandhi Unnayan Foundation (National Foundation for the Development of People with Disability)
KII	Key-informant interviews
MDG	Millennium Development Goals
NGO	Non-government organisation
OECD	Organisation for Economic Co-operation and Development
PABX	Private Automatic Bank Exchange
SMC	School Management Committee
SHG	Self-Help Group
TSC	Teachers-Students Centre
UP	Union Parishad
UN	United Nation
UNO	Upazila Nirbahi Officer (Sub-district based Executive Officer)
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VTCB	Vocational Training Centre for the Blind

Summary

Background

Globally, more than one billion people or 15 per cent of the total population are living with some form of disability with eighty per cent of them living in low and middle income countries (LMICs). People with disabilities often experience dependency and restricted participation in society; they have lower levels of access to health, education and livelihood services than their non-disabled counterparts. Equal participation of people with disabilities in societies is a priority for mainstream development, but people with disabilities and particularly those with multiple or severe disabilities, are often excluded from government and non-governmental development programmes, which leads to their further marginalisation and increased inequalities.

In South-East Asian countries, about 13 per cent of the population have moderate disabilities and 2.9 per cent have severe disabilities. Bangladesh has one of the highest prevalence of disability in the region, although estimates vary from 9 per cent to over 25 per cent depending on the study. Evidence on disability-related exclusion in LMICs, including Bangladesh, continues to be limited and there is only a handful of studies that explored the issue from the perspective of people with disabilities themselves.

Sightsavers, an international development organisation has worked with a range of partner organisations to implement a project titled 'Inclusive: Barrier-Free Inclusive Society for Persons with Disabilities'. The project aimed to promote equal participation of people with disabilities in socio-economic activities and community life and contribute to the delivery of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Bangladesh. The project was co-funded by Sightsavers and the European Commission.

The study presented here was integrated into this project and aimed to explore disability issues from different stakeholder perspectives; to examine knowledge of available health and rehabilitation services, as well as challenges and coping strategies, as experienced by people with disabilities and their families. The study was undertaken in collaboration with the International Centre for Diarrhoeal Disease Research, Bangladesh (icddr,b).

Methods

This was a qualitative exploratory study carried out between October 2014 and June 2015. Data were collected using in-depth interviews and focus groups discussions (FGDs).

The study population was adult men and women with disabilities as well as national and local stakeholders involved in the provision of disability-related policies and programmes. The study took place in Dhaka City Corporation (DCC) and Narsingdi district representing urban and rural sites of the project. A total of 33 persons with disabilities and 13 stakeholders took part in the study. Among people with disability, 17 had visual impairments, 14 had physical impairments and two had hearing/speech impairments. Other participants included government officials, service providers, parents and teachers of children with disabilities and representatives of non-governmental organisations (NGOs). The topic guide used in the study focused on knowledge and perception of disability; the role of the family in the life of people with disabilities; experiences of accessing health, education and other services; employment and livelihood opportunities; disability cards and allowances and skills training programmes.

All data were audio-recorded, transcribed verbatim and analysed thematically. The study was approved by the research review and ethical review committees of icddr,b. Study objectives and processes were described to all respondents in Bangla and a written consent was obtained in all cases.

Findings

Knowledge and perception of disability: Both people with disabilities and key stakeholders described disability through impairments and functional limitations. Many participants pointed out that their impairments leading to disability had been acquired in early childhood, often due to the lack of services and poor knowledge of where to get care in the case of an illness or an accident. Some impairments were caused by use of traditional remedies, particularly in rural areas. It was further noted that disability was often associated with blame, guilt and misfortune. Some people explained disability by supernatural powers or evil omen. Such views were often reinforced by the community, particularly traditional healers. Stigma and discrimination of people with disabilities were reported to be common in the study areas. Women with disabilities were more likely to experience stigma than their male counterparts. They were also more vulnerable to abuse and neglect in their communities.

The role of the family: Family was reported to be a critical source of support for people with disabilities. Most urban respondents lived in rented houses with other family members - their spouse, children or parents. Respondents in rural areas lived in their own houses but also with other family members. Help from others was particularly common for people with visual impairments and intellectual disabilities, but close proximity of family members ensured safety and security for people with disabilities, irrespective of their sex, age or type of disability. However, in some cases, the relationships with family members, particularly siblings, were reported to be complex and there was some evidence of discrimination of both adults and children with disabilities within their families. Some reported that they felt embarrassed by unnecessary sympathy shown to them, and a few stated that they were frequently addressed in derogatory terms. Female participants in both study sites were more likely to suffer from negative attitudes than their male counterparts. Parents of children with disabilities faced many difficulties. Mothers were reported to be the main carers; fathers were rarely involved in care, as they primarily provided money for living and seeking healthcare. Mothers often had to compromise their daily activities and earnings, particularly in the cases when the child required continuous day-to-day support. Some mothers reported experiencing physical and emotional distress.

Access to healthcare: Most respondents from both urban and rural areas mentioned that they frequently suffered from common health problems, such as cold, cough and fever. Most participants however agreed that the number of health facilities adapted to the needs of people with disabilities was very limited. The lack of accessible health clinics, difficulties with transport and financial constraints were the main barriers to healthcare reported by people with disabilities in this study. Many respondents in both urban and rural sites said that they did not go to healthcare centres and had no experience of either public or private healthcare services. Those who visited healthcare facilities mentioned several problems in accessing services, largely the lack of disability adjustments and negative attitudes of healthcare staff. Some people mentioned that they relied on international NGOs providing medical care. This was particularly common among participants with visual impairments.

Access to assistive devices: The use of assistive devices was common among urban respondents. Most people with physical disabilities in urban areas were using wheelchairs and crutches. People with visual impairments used white canes. Many urban participants obtained their devices from special schools for people with disabilities. They also received training on the use of their devices from NGOs and the majority said that they regularly used them. Respondents in rural areas also knew about different assistive devices received from local NGOs. The use of devices in these settings however was less common, as many people did not know where to buy them and how much they cost. People had to rely on local NGOs for supply, but NGOs did not provide any follow up services once the devices had been supplied. Respondents who used assistive devices reported numerous challenges they faced, including high costs, a need for technical knowledge on how to operate them and problems with maintenance and repairs.

Access to formal education: Access to education was identified as a key priority for people with disabilities. It was also reported that the Government of Bangladesh had provisions for stipends for students with disabilities and there was a quota system for people with disabilities in higher education. It was further explained that in recent years, the Government of Bangladesh had passed a legislation making the denial of education opportunities to a disabled child illegal. In practice however, there was a lack of adequate disability-friendly infrastructure; the lack of government provisions for educational materials, such as Braille books, and the lack of staff trained on disability in mainstream schools. As a result, opportunities of quality education were only limited to those students who could access expensive special schools located in urban centers. Transition to higher education and employment was also reported to be a challenge and many families believed that it was not worth educating their disabled child because they would not have a chance of employment and would always be dependent on other family members. In some cases, teachers also discouraged parents to enrol their children with disabilities to schools. This was particularly common for children with severe and complex disabilities.

Access to employment and sustainable livelihoods: Access to job opportunities and sustainable livelihoods has also been identified as a critical issue for people with disabilities. However, opportunities for regular paid jobs for people with disabilities were reported to be limited and available primarily to those with higher levels of education. Respondents who became disabled due to an illness or an accident had to leave their employment either voluntarily or involuntarily, as they could not earn as much as people without disability. The majority of people with disabilities interviewed in this study were not in regular paid employment and many were engaged in petty trade or begging. Inability to earn or perform household chores (for females) was one of the key concerns for people with disabilities in this study. As a result, many people felt that they were economic burdens and social liabilities to their families and frequently experienced embarrassment and shame. A number of participants pointed out to a quota system for recruitment of people with disabilities in the public sector. However, they said that the system was not always followed in practice and there were more applications from people with disabilities than the number of jobs available. It was also mentioned that getting a disability certificate, which was mandatory for the job application through this route, was lengthy and complicated. Some key informants also mentioned that there was a provision for interest-free government loans for people with disabilities. However, getting such a loan in practice was difficult because the overwhelming majority of people with disabilities were unable to pay back the loan, and the government officials were reluctant to provide them loans.

Rights and skills trainings for people with disabilities: It was reported that both NGOs and government institutions organised various types of trainings for people with disabilities. These covered both general awareness of disability rights and specific employment and

business skills. Although these training sessions were generally well received and appreciated by people with disabilities, they were not always tailored to the needs and aspirations of specific groups of trainees. Application of newly acquired employment skills was also difficult, as the number of jobs available to people with disabilities was limited and many people with disabilities did not have any capital to start up their own business.

Other aspects of social participation: Many people with disabilities reported facing challenges in seeking justice. It was further explained that in many judiciary institutions, there were no interpreters for people with hearing impairments. Where such services were available, they were inaccessible to people from rural areas and with low education, who did not know the formal sign language. Access to transport was also mentioned by several participants. It was reported that bus drivers did not always fully stop the bus and people with physical and visual disabilities could not get on it. Sometimes bus staff would be reluctant to let people with disabilities on the bus because they thought that people with disabilities would not be able to pay. Although the Bangladesh Disability Act makes provisions for up to eight seats on buses to be available for people with disabilities at a reduced price, the majority of respondents from rural areas were unaware of this provision and were not enlisted for the transport concession card. Overall, people with disabilities from urban areas reported more opportunities for social participation than those from rural areas. However, females were less likely to participate in community events in both urban and rural settings.

Disability cards and allowances: All respondents from both urban and rural areas knew about disability cards issued by the Government of Bangladesh. It was explained that the card was required for people with disabilities to be able to receive monthly government allowances and other entitlements. Respondents with the cards received their disability allowances from local banks. They generally reported no problems in receiving the allowances, as the bank staff arranged separate queues for people with disabilities on specific days and made adjustments to make the process more easily accessible. There was also a provision to receive money by an authorised person on behalf of a person with a disability. Receiving the disability card itself was reported to be more problematic, particularly in rural areas. Although most participants could obtain the card from their local village, there were challenges with the process. Some participants said that to receive a disability card one needed to either bribe a local official or be affiliated with the ruling political party. In some rural areas, local NGOs helped people with disabilities to obtain disability cards. However, there were restrictions on the number of cards available due to the limited resources allocated to the disability entitlements. Therefore, some local authorities could not issue cards to all people who required them. This was particularly the case in the localities where the Union Parishad chairmen did not come from the ruling political party.

Conclusion and policy implications

Study results show that there are many formal legal provisions for people with disabilities in Bangladesh. Examples include disability allowances and stipends, policy for mandatory enrolment of students with disabilities to schools, employment quota in the public sector, provision of interest free loans and discounted transport fares. However the findings also suggest that many people with disabilities are unaware of the existing legislation, the process of confirming eligibility for disability entitlements is complex and the resources allocated to the implementation of the existing legal frameworks are insufficient to cover all provisions for all people with disabilities.

The study has a number of policy implications:

Stigma and awareness raising activities:

- There is a need for further investment in awareness raising activities on disability and disability rights through families, community groups, service providers and mass media. The campaigns should target the general public, different stakeholder groups and people with disabilities themselves.
- Awareness of disability rights, existing policies and legal provisions should be built alongside clear mechanisms for holding decision-makers and service providers accountable for policy implementation. The role of Disabled People's Organisations (DPOs) is critical in exercising this accountability. Cases of disability-related discrimination (e.g. unlawful dismissals, violation of entitlements) should be systematically monitored and reported through the government and media reporting systems.
- All campaigns should be appropriately designed with clearly stated target audiences and behaviour change goals that they aim to achieve. There is also a need for rigorous evaluations of awareness raising and behaviour change campaigns to generate evidence on whether they achieve their intended goals and which approaches work better, for who and in which settings.

Access to health care and assistive devices:

- There is a need to join efforts with the organisations working to improve general health systems in Bangladesh, particularly in rural and deprived communities. It is critical to ensure that the general health systems in such locations have basic provisions to address common illnesses and accidents, which, if untreated, may lead to severe disabilities. Education of the general public and work with traditional healers is also critical to prevent inappropriate and harmful practices.
- Inclusive health approaches in general health facilities, including accessible premises and infrastructure, more appropriate working hours and positive attitudes of staff should be promoted and supported. Accessibility interventions should focus on different population groups, who may be at risk of exclusion, particularly women, children and older people with disabilities.
- There a need for a systematic assessment of assistive devices available to people with disabilities in Bangladesh alongside their prices, regulations, procurement and supply chain systems. Any improvements in the provision of assistive devices should include provisions for training and systems for maintenance and repairs. Initiatives to provide information and improve motivation to use assistive devices should be included in awareness raising campaigns.
- Special schemes to subsidise ultra-poor in accessing health care and assistive devices should be developed and tested.

Access to formal education:

- There is a need for a systematic review of the current educational provisions for people with disabilities and how they work in practice. As part of this review, it is important to assess to what extent inclusive education is being currently supported in the education sector plan and education budgets.
- There is also a need for comprehensive data on the current levels of inclusion of children with disabilities in schools and their academic outcomes. Such data could be generated through national population-based surveys and national education assessments disaggregated by disability.
- There is also a need for national and regional plans on how to improve enrolment and participation of children with disabilities in education at scale, and specifically identification and assessment of children with disabilities, accessible school infrastructure, educational support and teacher training, procurement of specialist educational materials, educational assessments and family and home support.

Employment, livelihoods and skills training for people with disabilities:

- There is a need for a systematic review of the current employment provisions for people with disabilities (e.g. public sector quotas) and how they work in practice.
- Bespoke skills training programmes for people with disabilities should consider individual characteristics of trainees, their aspirations, as well as the contexts and labour markets in which the newly acquired skills will be applied.
- Livelihood programmes focusing on the provision of equipment and tools should make provisions for maintenance and repairs.
- Employer schemes promoting and supporting access of people with disabilities to jobs should be piloted and rigorously evaluated to ensure learning from such schemes is widely disseminated and used.

Other social inclusion measures:

- There is a need for a review of the system of the provision of disability cards to ensure that the process is transparent and clear to people with disabilities and that all who are entitled to have a card can access it. DPOs should be considered as local intermediaries facilitating this process.
- There is a need for a review of the subsidised transport system, how it works and what the bottlenecks in the implementation are. This should be followed by specific recommendations on how the system can be improved, including raising awareness of the scheme among people with disabilities, developing systems to ensure the entitlements work in practice (e.g. transport cards) and developing mechanisms of reimbursements to transport providers.
- There is also a need for more inclusive judicial practices, including systems of legal aid to people with disability (e.g. through DPOs) and disability inclusive courts and other legal institutions.

Introduction

Globally, more than one billion people or 15 per cent of the total population are living with some form of disability with eighty per cent of them living in low and middle income countries (LMICs) [1, 2]. Between 110 and 90 million people have very significant difficulties in functioning. People with disabilities are more likely to be unemployed than non-disabled people. They often experience increased dependency and restricted participation in their societies [3, 4].

Although the definition of disability is widely varied between the countries, a conceptual framework of the World Report on Disability describes it, as "... the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"[2]. Equal participation of people with disabilities in societies is a priority for mainstream development and social progress [5].

In South-East Asian countries, about 13 per cent of the population have moderate disabilities and 2.9 per cent have severe disabilities [2]. Bangladesh, being an overpopulated low income country has one of the highest prevalence of disability in the region [6], although the estimates vary from 9 per cent to over 25 per cent depending on the study [7; 8]. The main causes of disability are reported to be birth defects, accidents, chronic illnesses, negligence, malnutrition and poor access to health and disability-related services [5].

People with disabilities in Bangladesh are often neglected, stigmatised and discriminated against [9, 10]. They often experience poorer health, lower education and fewer economic opportunities than people without disabilities [10, 11]. Poor general health coupled with inability to participate in social life often lead to anxiety, depression and other mental health issues [12]. Women, children, older people and those from the poorest backgrounds are particularly vulnerable to discrimination and neglect [11]. Women and children with disabilities often experience violence and abuse [13; 14]. People with disabilities, and particularly those with multiple or severe disabilities, are usually excluded from government and non-governmental development programmes, which leads to their further marginalisation and increased inequalities [15].

Disability issues are insufficiently explored in Bangladesh; and it is only in the last decade, the Government of Bangladesh started recognising social exclusion of people with disabilities [16]. But the evidence on disability-related inequalities in LMICs, including Bangladesh, continues to be limited [17]; and there is only a handful of studies that explored the issue from the perspective of people with disabilities themselves [18]. Therefore it is important to undertake more studies that examine knowledge and experiences of people with disabilities, their families and communities; it is important to understand how people with disabilities perceive their environment, how they interact with the services available to them and what opportunities they see for the promotion of disability rights and their full social participation.

This study was implemented in the context of a programme titled "Inclusive": Barrier-free Inclusive Society for Persons with Disabilities" supported by Sightsavers, an international development organisation working to eliminate avoidable blindness and promote equality of opportunities for people with disabilities. The study was co-funded by Sightsavers and the European Commission (EC), and was undertaken in collaboration with the International Centre for Diarrhoeal Disease Research, Bangladesh (icddr,b).

Materials and Methods

Study objectives

The overall objective of this study was to explore disability issues from different perspectives; to examine knowledge of available health and rehabilitation services, as well as challenges and coping strategies, as experienced by people with disabilities and their families.

The specific objectives of the study were:

1. To examine the perception of disability-related issues by people with disabilities and their family members;
2. To explore the role of the family and community in supporting people with disabilities;
3. To explore the knowledge and experiences of health and rehabilitation services provided in the study areas; and
4. To identify barriers and facilitators of social inclusion of people with disabilities.

Study design and study areas

This was a qualitative exploratory study conducted between October 2014 and June 2015 in Narsingdi district and Dhaka City Corporation (DCC) area of Bangladesh. These were the locations of the inclusive programme supported by Sightsavers. The study used in-depth interviews and focus group discussions (FGDs) approaches to collect data.

Study population and sampling

The study population included adults with disabilities, parents of children with disabilities, schoolteachers, national and local government representatives, (at the district level and below) and programme partner organisations and personnel (Assistance for Blind Children (ABC), Narsingdi Nari Unnayan Sangstha, PAPRI).

Study participants were purposefully selected from the lists of programme stakeholders and beneficiaries. In total, 33 persons with disabilities (physical (n=14), visual (n=17), and speech (n=2)) and 13 stakeholders (government officials, service providers and parents of children with disabilities) participated in the study (**Table 1**). Participants were recruited to represent a range of factors (i.e. location and socioeconomic status of the household, sex, age, and type of disability).

Table 1. Study participants

Number of respondents and data-collection technique	Respondent characteristics
33 in-depth interviews	Persons with disabilities (22 in Narsingdi and 11 in Dhaka)
13 key-informant interviews	<p>a. Two project programme staff in Narsingdi</p> <p>b. Two policy-level officials</p> <p>c. Nine service providers (6 in Narsingdi and 3 in Dhaka):</p> <p>Rural: Social Welfare Officer (SWO), Upazila Nirbahi Officer (UNO)/Upazila Health & Family Planning Officer (UHFPO) from two purposively selected upazilas, one accessible from the highway and the other one in remote area</p> <p>Urban: Health officials, social welfare officials, and elected local representatives from the study area</p>
Three (3) Focus group discussions with parents	One with mothers of children with intellectual disabilities and two with male and female parents of children with physical and sensory disabilities; six to eight parents in each group
One (1) group discussion with Union Parishad (UP)	Three purposefully selected chairmen from three upazilas of Narsingdi district
One (1) focus group discussions with teachers	Six teachers of mixed sex involved in educating children with disabilities in Narsingdi district

Data collection

Unstructured and semi-structured topic guides were used to facilitate interviews and FGDs. Interviews were conducted at the participants' home, places of work or a convenient location in their community. Each FGD included between six and eight participants. All FGDs and interviews were facilitated by trained moderators/interviewers.

The field team included four research officers trained in anthropology and two supervisors. Prior to the study, the team had received a one-week training on qualitative research methods and study objectives and procedures.

Two supervisors monitored data collection in the field to ensure data quality. Regular sessions with the field team were conducted to discuss issues related to data collection and provide feedback.

Data analysis

All interviews and FGDs were audio-recorded and transcribed verbatim. In addition, all interviewers maintained diaries with day-to-day details, including field experiences, personal observations and any incidents during the fieldwork. These field diaries supplemented the transcripts and interpretation of data during the analysis.

Data was transcribed and analysed thematically in Bangla. The transcripts were read to develop codes and sub-codes. This was followed by data categorisation, which included the identification of salient themes and subthemes and recurring patterns. The themes were further organised and aligned with the research objectives for the presentation in the study report.

Ethical clearance

The study was approved by the research review and ethical review committees of icddr,b. The study objectives and processes were described to all respondents in Bangla and a written consent was obtained in all cases. Efforts were made to ensure that all respondents understood that their participation was voluntary, and they could withdraw their consent at any time. In a few cases, where people with disabilities were not able to sign their consent, the consent was obtained from their guardian (a spouse or a relative). All interviews took place in private locations selected by the respondents. During the interviews with the respondents with speech disabilities, a local interpreter or a relative was present.

Findings

Characteristics of study participants

In total 33 people with disabilities took part in the interviews (22 in Narsingdi and 11 in DCC). Twenty-one participants were male and 12 were female. The majority were married. The majority had either visual impairments (17) or physical disabilities (14). Two respondents had hearing and/or speech disabilities (Table 2). Thirteen key informants included nine service providers, two government officials and two programme staff.

Table 2. Demographic characteristics of the people with disabilities

Characteristics	Narsingdi (Rural)		Dhaka (Urban)	
	Male (n=13)	Female (n=9)	Male (n=8)	Female (n=3)
Type of disabilities				
Visual	6	5	4	2
Physical	6	3	4	1
Speech	1	1	0	0
Education				
Primary (up to Class V)	12	6	1	0
Secondary (Class VI-X)	0	2	4	1
Higher secondary	1	1	3	2
Marital status				
Married	12	4	6	2
Unmarried	1	3	2	0
Divorced	0	1	0	1
Widowed	0	1	0	0

Disability knowledge and perceptions

Both people with disabilities and key informants participating in the study had limited knowledge and understanding of disability. Many described disability through impairments and inability to perform certain functions (e.g. walk, speak) or work.

The causes of disability, as described by study participants, were multiple and included congenital disability, accidents and illnesses. Some mentioned supernatural powers or

events, as causes of disability. Some, particularly those in rural areas, considered disability to be a curse of God or evil souls, and many respondents regarded their disability as ill fate.

Participants with congenital impairments learnt about their disability from their parents, who recognised disabilities by physical signs, for example, inability to move, crawl, walk or talk; white eyeballs or marks in the eye, or inability to understand instructions or control emotions. This is how the mother of a child with a disability described her experiences:

"He was then 2-3 years old. When we called him, he did not respond; even he did not respond to any loud noise, such as miking [announcement made using loudspeaker]. We called his name from a very close distance, but he did not respond."

Some respondents said that their disability was inherited from their parents and in such cases, the parent perceived to be responsible was blamed and stigmatised by other family members. A male participant shared his experience:

"I feel really bad when my relatives say that I got this problem from my grandfather. My mother has to listen to such words. My father sometimes says that it would not have happened if he had not married my mother."

Respondents who acquired an impairment, as a result of a disease also heard about their disability from their parents. Diarrhoea, kala-azar, and typhoid were reported to be the main diseases that resulted in disability:

"My father told me that I was absolutely fine since my birth. Suddenly, I started suffering from fever. It was called kalajor [kala-azar]. After suffering from that fever, I got a problem in my legs. They did my treatment, but it was not cured."

Some respondents explained their disability by misdiagnosis or lay treatment by a family member or someone in the community. This is how one respondent described her experiences:

"It [my leg] became a sore. To remove bad blood inside ... my father cut it with a piece of broken glass...he was like a man of old age. He had no knowledge...he used to do whatever he found better. After the sore was cut, my left leg became shorter. I had a step-mother, and she tried to stretch my leg to fit it, but my leg became curved."

Delayed treatments were often named as a reason for disability in rural areas. The delay was largely due to poor knowledge of what to do and where to seek care. For many rural residents, traditional healers (Kobiraj), were the only providers of care they could access. One of the parents described her frustration:

"I took my child to one Kobiraj, to another Kobiraj but nothing worked."

Urban respondents were largely aware of specialist healthcare facilities but could not access them due to family financial constraints and reluctance of household decision-makers to seek or pay for care. A female participant described how it happened in her family:

"My child's condition was severe, and his father decided not to go for an operation. He decided to delay the treatment as our financial condition was bad... "

Some respondents described how they became disabled as a result of an accident, often a road accident or an injury at work. Some reported that following their accident they were unknowingly mistreated or ill advised by relatives or neighbors, and this mistreatment led to disability, as described by one of the participants with visual impairment:

"It was in the month of Falgun... I was sitting under a tree. A sudden whirl of wind came, and some sand particles got stuck in my eyes. Then, some of the female neighbours suggested my grandmother to put onion fluid into my eyes so that the sand particles would be removed. After that, I lost my right eyesight and, a few days later, I lost my left eyesight as well."

Some participants, who associated their disability with supernatural powers, reported feelings of guilt or wrongdoing. This view was particularly common for parents of children with disabilities, who believed that they had done something wrong during pregnancy or childbirth. Such view was often enforced by the community members- neighbours or spiritual healers. For example, one mother described how she believed that her son was born disabled because she did not follow the restrictions during the time of the moon eclipse. Some parents believed that their child had been attacked by evil spirit in the womb.

"The Kobiraj told me that a bad jinni caught me, when I went close to the well during my pregnancy. It attacked my foetus. The Kobiraj confirmed that was a mad jinni!"

"Our Kobiraj told us about it...when my child grew up and was supposed to start walking, he could not walk...he could not even eat. Seeing these, we talked to the Kobiraj, and he told us about this curse."

The role of the family and community in the lives of people with disabilities

Many people with disabilities participating in the study could not manage their daily activities independently and had to seek help from others, for example mothers, siblings, other family members, and neighbours. Most urban respondents lived in rented houses with other family members - their spouse, children or parents. Respondents in rural areas lived in their own houses but also with other family members.

Help from others was particularly common for people with visual impairments and intellectual disabilities but close proximity of the family members ensured support and security irrespective of the type of disability. Family help was thought to be particularly critical at the early stages of life. Over time, many people with disabilities grew up and gradually learnt to cope, although this was much more challenging for people with intellectual disabilities.

For people with physical disabilities, movement from one place to another was the main problem in both urban and rural areas. Both male and female participants tried to get married early, so that their spouses could help them to move and perform physical tasks.

Communication problems were the main barrier for people with speech and hearing disabilities. Their family members used sign language or simple gestures. When a person with speech and hearing disability needed to go to a place outside their village, relatives would write down the address of the destination, which was then shown to other people in the street or bus drivers.

Respondents with visual disabilities mentioned that seeking help from others was an important coping strategy, particularly for crossing a busy road or finding a new place. Pedestrians and the police often helped them in such situations.

Relationships within the family were reported to be challenging for people with disabilities. All study participants with disability mentioned that they were treated differently from non-

disabled members of the family. Some reported that they felt embarrassed by unnecessary sympathy shown to them, and a few stated that they were frequently addressed in derogatory terms. Female participants in both study sites were more likely to suffer from negative attitudes than their male counterparts.

While many respondents reported that they were considered important by their family and were involved in decisions regarding different family matters, some said that their siblings deprived them from their inherited land or property because they had to take care of them:

“My brother said that I don’t need any property because I am living with him. Ultimately, I never saw any cash or kind from my property. All of these are owned by my brother”

Respondents from both urban and rural areas said that it was difficult to arrange a marriage for a person with disability. For females, their family tried to find a man with a disability. If unsuccessful, they would try to find a poor man, who they would pay a dowry and help to establish in life. In some cases, the family would try to arrange a marriage of their daughter with a disability with a cousin, expecting that their married life will be peaceful, given that they are relatives. All married women with disabilities said that they had been asked for consent before marriage.

Men with disabilities said that they were not required to give a dowry, but they also faced difficulties in finding a bride. Sometimes a poor family with a non-disabled daughter for whom they cannot pay a dowry would agree for their girl to marry a disabled man. About half of the respondents agreed that informing the family of the spouse about disability prior to the marriage was important.

Acquiring disability after marriage was also discussed by study participants. Many referred to disability as a turning point in their lives, as almost everything changes for the individual concerned. One male and one female respondent reported that they had been divorced by their spouses because of their disability.

Parents faced many difficulties in taking care of their children with disabilities. Mothers were the main carers. Fathers were rarely involved in care as they primarily provided money for living and seeking healthcare. The same applied to older brothers, while sisters were expected to help their mothers and to take over the carer responsibilities, when the mothers were not available. Mothers often had to compromise their daily activities and earnings, particularly in cases when the child required continuous day-to-day support. In some cases, heavy workload coupled with the parent’s fear for their child’s future resulted in mother’s physical and emotional distress and mental health breakdown, as indicated in the quote of one mother in this study:

“I am sick and tired. Sometimes, I say to him [my son] ‘go and die!’ I don’t know what will happen if I die.”

Children with intellectual disabilities were reported to be particularly vulnerable, as they were often stigmatised or even abused by their siblings. This is how one mother explained the relationships between her children, one of whom had a disability:

“My daughter is younger than her disabled brother, but she does not respect him because he does not have any intellect. She refuses to take food or water in the same utensils that are used by her disabled brother.”

Availability of assistive devices for people with disabilities

The use of assistive devices was common among urban respondents. Most people with physical disabilities in urban areas were using wheelchairs and crutches. People with visual impairments used white sticks and black glasses. Six out of eight males and all three female participants in urban areas knew about assistive devices, where to get them and how much they cost. Many urban participants obtained their devices from specialised schools for people with disabilities. They also received training on the use of their devices from NGOs and the majority said that they regularly used them. An exception was public gatherings and social events, such as weddings, mainly because of the unwillingness to disclose disability to other people. The use of assistive devices seems to be higher among men in urban areas, although the number of participants was too small to make any definitive conclusions.

Respondents in rural areas (eight out of 13 males and seven out of nine females) also knew about different assistive devices, because local NGOs, such as ABC, provided them with information. The use of devices in these settings however was less common, as many people did not know where to buy them and how much they cost. People had to rely on local NGOs for supply, but NGOs did not provide any follow up services once the devices had been supplied. Some respondents from rural areas mentioned assistive devices that were locally made using local material, such as tree-branches, bamboo, and unused bearing.

Respondents who used assistive devices reported a number of challenges they face, including high costs of the assistive devices, a need for technical knowledge on how to operate them and problems with the supply of batteries for hearing aids.

Access to healthcare services

Most respondents from both urban and rural areas mentioned that they frequently suffered from common health problems, such as cold, cough and fever, which were not related to their disabilities. Respondents with visual impairments were particularly vulnerable to infections. Most participants however agreed that the number of health facilities adapted to the needs of people with disabilities was very limited. Five out of 11 respondents in urban areas mentioned that they were aware of a specialist hospital nearby but did not know who ran the hospital or which types of services were available there. Only one urban participant reported that there was a separate unit for people with disabilities in a government hospital they visited. However, to access this facility, a person with disability needed to show a certificate as a proof of disability. Limited numbers of facilities, difficulties with transport and financial constraints were the main barriers to healthcare reported in this study. As a result, many respondents in both urban and rural sites did not go to healthcare centres and had no experience of either public or private healthcare services.

Some people mentioned international NGOs who supported health programmes for people with disabilities. This was particularly common among participants with visual impairments. Thus, one male respondent mentioned the Rotary Club, who organised events for people with visual impairments, provided free eye treatment and surgeries at subsidised fees. Another organisation, Sandhani, provided medicines to people with visual impairments discounted at 20 per cent of the market price. Some participants with visual impairments also knew about the Lion's hospitals because ABC collaborated with these hospitals. Free treatments for people with visual impairments were also provided by either NGOs or

pharmaceutical companies on national public holiday days, such as Victory Day, Independence Day and others.

Those who visited healthcare facilities mentioned several problems in accessing services, largely the lack of disability-friendly facilities or adjustments at the ticket counter or in front of the elevator, and attitudes of some hospital staff.

Some participants preferred to go to private doctors because there was no waiting time involved. One respondent who was a beggar, described that to seek medical care he often illegally crossed the border to India. He further explained that he had made friends with the border guards on both sides and they let him pass whenever he needed a treatment:

“In India, they [doctors] are so polite to me, which influenced me to visit them frequently.”

Female respondents reported visiting government facilities only, and they were not aware of any specialist facilities for people with disabilities.

Access to education

The majority of study participants attended primary school (up to Class V) only. Respondents from urban areas were more likely to have secondary or higher education than those from rural areas and only two males had completed a master’s degree. Many participants said that they had to leave school due to disability.

Many participants noted that there were a limited number of disability-friendly educational institutions and most of those were in urban areas. Historically, there had been a quota system for students with disabilities in some schools but recently, an official order was sent to all schools stating that it was mandatory to enrol students with disabilities and the schools that refused to do so could lose their registration. It was also noted that the government provided stipend for students with disabilities based on their academic merits. However, there was no government provision for educational materials, such as braille books, for mainstream schools and there was no disability-related training for teachers in mainstream schools.

Respondents with disabilities who attended schools reported that only special schools located in urban areas provided disability-friendly environments and infrastructure. Most mainstream schools in both rural and urban areas did not have trained teachers or educational materials to adequately support students with disabilities. The school infrastructure, including school buildings, classrooms, benches and toilets, was not adapted to the needs of students with disabilities.

The lack of interest and motivation among parents of children with disabilities was reported to be an important barrier. Many families believed that it was not worth educating their disabled child because they would not have a chance of employment and would be always dependent on other family members, as one female participant explained:

“I was interested to continue my study [but] my brother told me I don’t have to go to school. ‘Who will employ you? We will look after you. ‘Then... I stopped going to school.”

In some cases, teachers discouraged parents to enrol their children with disabilities to schools. This was common for children with complex disabilities, such as severe visual or speech impairments or intellectual disabilities. The lack of appropriately trained teachers,

education materials and other facilities were reported to be the main factors discouraging schools to enrol children with disabilities:

“I thought if he [my son] attends school, he would learn something, but the teacher discouraged me and said that he does not have capability to learn anything, this will be a total waste of time”.

In rural areas, ABC motivated School Management Committees (SMC) to encourage parents to enrol their children with disabilities in schools through monthly committee meetings and occasional home visits. ABC also provided books and other educational materials to support children with disabilities in schools.

Most respondents who attended mainstream schools in both urban and rural areas said that they had experienced positive and friendly attitudes from the teachers and classmates. This however was more common in schools, where teachers had been trained on disability. These teachers were aware of how to inspire children with disabilities and gave significant attention to their learning. Classmates in such schools were also very supportive, helping students with disabilities with organising their books, preparing class notes and accompanying them to school and back home.

Teachers who didn't receive training on disability were not so friendly. They did not want to spend extra time required by children with disabilities. They were also concerned about the impact a child with a disability may have on learning of other students. One male participant recalled how the headmaster in his village refused to enrol him because of the fear that other parents might withdraw their children from the school:

“My father tried to admit me to school but failed. He tried his best...now I am here in the street and begging for my survival”.

Some respondents mentioned that their slower way of learning and frequently asking questions often annoyed their classmates in mainstream schools. They however learnt to ignore such behaviours and focused on their studies.

Respondents from urban areas reported experiencing fewer barriers to education, as there were special schools for children with disabilities in these areas. It was noted that all teachers and other school staff in special schools were trained to support students with disabilities. Moreover, all students in special schools had a disability, and there was a feeling of common experiences and mutual support between the students, as one adult with visual impairment explained:

“I felt really happy at that time. I felt that O Allah! All are the same, as me...they all had no eyesight like me. So, I had a number of friends here who are like me. I am not the only one. So, I forgot my grief. Why should I be sad? We had a big playground at our school and also a nice garden. We could play. All support staff and our teachers were very nice and friendly.”

All participants who were aware of special schools said that these schools were available only in urban areas and they were expensive. Urban respondents who were educated to secondary level or higher reported that they had attended special schools and had had support from their family, teachers and friends. However, transition to higher levels of education was difficult even for these students because most special schools provided education up to Class VII only. After that, students were expected to attend mainstream schools and colleges, where there was no accessible environment, as one female respondent from Dhaka explained.

“There were no books written in braille...I had to record all the lectures...Some students like us, preferred to write it down on a special page that cost ten taka per piece. Some students wrote it [for us] for money...they used to write for me as well. I completed my higher secondary certificate examination in this way.”

Other respondents with visual impairments mentioned that they faced problems during public examinations, as they had to hire a writer and pay for his services. Other participants said that, although higher education had quota for disabled students, the application process was lengthy and bureaucratic, as they had to apply for a disability certificate first.

Teachers participating in FGDs made a number of recommendations on how to improve disability-related training for teachers. First, the duration of the course should be longer than 10 days and focus on different types of disabilities. Teachers also needed refresher courses because they did not have students with disabilities every year and could easily forget their initial training without practice. Additionally, teachers recommended increasing disability stipends to encourage poor families to send their children to schools. They further suggested providing stipends at the union rather than upazila level, which was less time-consuming and less costly. Another recommendation was to ensure that students with different disabilities had access to assistive devices:

“They [ABC] have provided devices for students with visual impairment but for students who are hearing-impaired, there are no devices.”

Economic opportunities and access to employment

Most participants said that disability had a profound negative effect on their employment opportunities. Respondents who became disabled due to an illness or an accident had to leave their employment either voluntarily or involuntarily, as they could not earn as much as people without disability. Some started begging, as a result. The majority of people interviewed were not in regular paid employment and many were engaged in selling small goods (mobile phone covers, toothbrushes, water bottles, chocolates) or begging. Inability to earn or perform household chores (for females) was one of the key concerns for participants in this study. As a result, many felt that they were economic burdens and social liabilities and experienced embarrassment, guilt and shame.

Those who had small businesses in the street often faced problems. One male respondent with visual impairment said that his rice selling business failed because he could not weigh his products, which caused him financial losses. Petty traders with visual impairments were often cheated on by their customers because they could not see the banknotes:

“A fifty-taka note and a twenty-taka note are similar in size and thickness! So, I faced difficulties in these situations. I have to ask someone to help me and sometimes, some men whom I ask for help steal [my] money.”

Capabilities of physically disabled people were often questioned by the customers. For example, a rickshaw-puller with one hand often faced questions from the passengers whether he was capable to pull on the rickshaw. Females with disabilities who were involved in begging in buses were often abused by the bus staff.

A number of study participants said that only people with disabilities who were adequately educated could have well paid jobs in the public or private sectors, including banks, academic institutions, NGOs and government offices. Two respondents from urban areas,

who had master's degrees, knew that there was a quota system for recruitment of people with disabilities in the public sector. However, they said that the system was not always followed in practice and there were more applications from people with disabilities than the number of jobs available. It was also mentioned that getting a disability certificate, which was mandatory for this job application route, was lengthy and complicated.

Some key informants mentioned that there was a provision for interest-free government loans of 10,000 to 20,000 taka for people with disabilities. The repayment on such loans was frozen for the first six months. After that people with disabilities had to pay 1000 taka per month. However, getting such a loan in practice was difficult because around 90 per cent of people with disabilities were unable to pay back the amount required, and the government officials were reluctant to provide the loan.

Disability card and disability allowances

All respondents from both urban and rural areas knew about disability cards issued by the government. The card was used to receive monthly allowances from the government. Respondents with the cards from rural areas drew disability allowances from their local branches of Sonali Bank. They experienced no problems in receiving the allowance, as the bank staff arranged separate queues for them on specific days, and although the bank office was often located on the upper floors, the bank staff would come down to distribute the money. There was also a provision to receive money by an authorised person on behalf of a person with disability.

Receiving the disability card itself was more problematic, particularly in rural areas. Among 22 rural respondents participating in the study, six did not have a disability card. Although most participants could obtain the card from their local village, there were challenges. Some participants said that to receive a card one needed to bribe local officials or be affiliated with the ruling political party. There were also restrictions on the number of cards available due to the limited resources allocated to the disability entitlements. For example, one female respondent explained that she had been informed about disability cards by her neighbours. She then contacted the Union Parishad (council) member (an elected member of the union council, one of the lowest tiers of the local government). The UP member told her that it would require some money to get the card. She gave him 1100 taka without asking the reason. She had to visit the local leader's place several times and, eventually, she got the card with the help of her cousin who was the chairman of the Union Parishad.

In some rural areas, local NGOs helped people with disabilities to obtain disability cards. However, the number of disability cards allocated per union parishad was limited. Therefore, some local authorities could not issue cards to all people, who required them. This was particularly the case in the localities where the Union Parishad chairmen did not come from the ruling political party.

Other aspects of social participation

Many people with disabilities reported facing challenges in seeking justice from legal institutions. In many judiciary service centres (district courts), there were no interpreters for

people with hearing and speech impairments. A few centres that provided sign interpreters were still not accessible for the local populations because many people did not know the formal sign language. They were used to their own signs/gestures, which they learnt in their family. In such situations, people with hearing impairments or speech disabilities could not communicate or understand proceedings of the court.

Access to transport was also mentioned by several participants. Some participants explained that bus drivers did not always stop the bus and people would get on, when the bus was still moving. People with physical and visual disabilities could not do it. They would ask the driver to stop the bus and wait. Some bus drivers would be responsive to the request, while others would not. Some participants also mentioned that staff were often reluctant to allow them getting into the bus because they thought that people with disabilities would not be able to pay the transport fare. Although the Bangladesh Disability Act makes provisions for up to eight seats on buses be available for people with disabilities at a reduced price, the majority of respondents from rural areas were unaware of this provision and were not enlisted for the transport concession card. These respondents said that they had to pay the same fare as other passengers or rely on the good will of the bus staff to allow them a free journey.

Overall, most respondents from rural areas said that they did not participate in common community activities, such as sports, shopping, ceremonies, cultural functions and religious festivals. In urban areas, the situation was different; here people with disabilities reported more opportunities for social participation. However, females were less likely to participate in community events in both settings.

Legal provisions and services for people with disabilities

Findings from the key informant interviews in both rural and urban areas suggest that both the Ministry of Social Welfare and NGOs provided a range of services targeting people with disabilities. The Government support focused mainly on financial entitlements (disability allowances and scholarships or stipends), skill development training and priority-based services for people with disabilities. NGOs supported mainly on awareness-raising activities, education, training and therapy. Table 3 below shows the organisations working on disability in Bangladesh and some of their activities.

Table 3. Some of the organisations working for the people with disabilities in the study areas

Sl. no.	Name of organisation	Working area	Type of organisation	Type of services/activities
1	Department of Social Services (DSS) and its offices under the Ministry of Social Welfare (MoSW)	National level	Public/ Government of Bangladesh	Policy-making, providing disability allowance, loans for small businesses, stipends, treatment, awareness of rights, education, coordination with NGOs
2	Jubo Unnayan Proshikkhon Kendro (Youth development and training centres)	National level	Public/ Government of Bangladesh	Skill development training

Sl. no.	Name of organisation	Working area	Type of organisation	Type of services/activities
	under the Ministry of Youth and Sports			
3	Jatiyo Protibondhi Unnayan Foundation (National Foundation for the Development of People with Disabilities) under MoSW	National level	Public/ Government of Bangladesh	Policy-making, advocacy with different ministries, various types of therapies utilising its 103 centres located at district and upazila (sub-districts) levels and through mobile vans
4	Assistance for Blind Children (ABC)	Narsingdi	NGO	Integrated education programmes for visually impaired children, promotion of rights of people with disabilities, skill development training, management development training, training on the use of assistive devices, referrals
5	BRAC	National level	NGO	Awareness for education, identifying disabled persons
6	Narsingdi Nari Unnayan Songstha	Narsingdi	NGO	Primary treatment, referrals for speech therapy, occupational therapy, distribution of devices, income-generating skill development
7	PAPRI	Narsingdi	NGO	Promotion of rights of disabled people, treatment, assistive device distribution, education, loans (group), training
8	Lions Club	National level	NGO	Devices for vision-impaired people, surgeries for vision impaired people
9	Gram Bikash Kendro	Narsingdi	NGO	Education, work with government programmes
10	Protibondhi Kallyan Samiti	Dhaka	NGO	Device-making
11	Ashar Alo	Narsingdi	Local voluntary organisation	Awareness raising
13	Spondon	Narsingdi	Local voluntary organisation	Self-health group formation (SHG), training, arranging loans for disabled people, communication of information
15	Sightsavers	Both the field sites/ national and	INGO	Partner capacity-building, SHG/DPO support and skills development, advocacy, generating and disseminating evidence and learning, eye health care and inclusive education

Sl. no.	Name of organisation	Working area	Type of organisation	Type of services/activities
		international level		
16	Centre for Disability and Development	National level	NGO	Technical support for local NGOs

Key informants from the Government stated that there were many policy provisions for people with disabilities. According to the Government policy, all people with disabilities have the right to free primary education, health services, employment opportunities, and allocated seats on transport. The knowledge of the key informants however was generic, and very few officials referred to specific acts or legislation. This is how one key informant described his understanding of the Government policy framework with regards to disability:

“I cannot say about each and every section of the policy related to the rights of persons with disabilities but in some sectors, persons with disabilities are given priority. And in the health sector, in sub district hospitals, district hospitals, everywhere, they [persons with disabilities] are given priority for accessing healthcare, and all these are in the law; so, within the law, we are trying to provide them services.”

Some key informants suggested that many people with disabilities were unaware of government provisions and could not exercise their rights. Therefore, raising awareness and educating people with disabilities about their rights was named to be the key Government priority:

“Policies ... formulated by the Government are friendly for persons with disabilities but the policies are not being implemented properly. For example, disabled students have special quota for school enrolment, but they do not know about this and as a result, they cannot apply their right.”

Informants from the NGOs participating in the study said that the previous Disability Act was based on welfare principles and focused on the dependency of people with disability on others. Under the current Act, every sector and organisation should treat people with disabilities as a priority group and provide them with financial and logistical support. The main principles of the new Act introduced in 2013, is to protect and empower people with disabilities. Many NGOs changed their activities towards educating people with disabilities about their rights and encouraging them to exercise their rights. Some communities however, still had expectations of getting help from others, which created a challenge for NGOs, which focused only on awareness raising activities.

Key NGO informants referred to a number of special provisions for people with disabilities. For example, the new Disability Act clearly stated that a person with a disability could study in any institution and it was their right. If an institution refused to admit a child or an adult with a disability to education, this was a criminal offence.

There are also the White Cane Safety Measures, where vehicles on the road must stop to give way to a person with a visual impairment carrying a white cane, when crossing the road. Some NGO participants however, criticised the government for the inadequate implementation of these policies and suggested the government could do more to enforce disability legislation.

The knowledge of the rights of people with disabilities among people with disabilities participating in the study varied. Most participants educated to the secondary level or higher were aware of their rights and government provisions for people with disabilities. They obtained their knowledge mainly from NGOs.

Less educated participants had limited knowledge of disability rights. These participants believed that they had the same rights as other people but could not articulate what these rights were or how to exercise these rights. Some heard about their rights from different training sessions organised by NGOs, but many could not remember details.

A number of participants mentioned a discrepancy between the existing Act on Disability and its implementation in practice. For example, a number of respondents said that people with disabilities had a right to education, but the education system was not inclusive, as most schools in Bangladesh lacked an appropriate infrastructure. Also, although there was a quota system for employment of people with disabilities in the public sector, it did not apply to other sectors. In addition, the working environments were not inclusive for people with disabilities. Employers were reported to be reluctant to recruit people with disabilities due to the perceived limited capacity of people with disabilities. Furthermore, although disability allowances were formally in place, many people with disabilities faced difficulties in getting them, because they could not get a disability card. Finally, voting was also reported to be an issue for people with disabilities because waiting in long queues of voters was not an easy task for persons with disabilities.

Training for people with disabilities

Most participants from Dhaka received training from NGOs, such as Bangladesh Visually Impaired People's Society (BVIPS), Centre for Disability in Development (CDD) and Sightsavers. The only urban participant who reported not having been trained, said that he did not have time and did not want to participate in the training offered. Most people with disabilities received training on PABX and telephone operating, computer, stitching, weaving, packaging, catering, disaster management, and legal rights. People with visual disabilities received training on orientation and mobility, where they learned how to move from one place to another. Usually, this was a home-based one-to-one training where a trainer came to the trainees' place and trained how to move alone with a white stick. Only one study participant mentioned that he had been trained to use sign language.

In Dhaka, two female participants received training from the Government Vocational Training Centre for the Blind (VTGB), which provides training on PABX, telephone and computer operating, candle-making, stitching, therapy, weaving, making bags, and book binding. All training sessions were accessible and disability friendly. For example, during the computer training for people with visual impairments, the trainers used a 'talking software'.

One rural female respondent received training on mobility from the BAPTIST mission school. She also attended a 5-day training programme on spoken English by the Helen Keller International at Dhanmondi, a one-day training on playing chess at the Teachers-Students Centre (TSC) at the University of Dhaka, and a three-day training on disaster management from BVIPS. All training sessions provided snacks and lunches. The disaster management training was delivered by government officials, NGO staff and university lecturers. Participation in training was limited to the members of self-help groups.

Most respondents said that the training sessions were delivered on convenient dates and time, and participants' food, accommodation and transport costs were covered. Some participants however, said that the computer training of nine months was not sufficient to learn computer operation properly. At the trainees' request the training was extended by two more months.

Study participants who received training agreed that the training courses empowered them and increased their skills and confidence. The training helped them feel more optimistic about their life and opportunities for accessing public and private sector jobs. For example, one respondent explained how attending his training helped him overcome his hesitations about doing a new job and improved his confidence. Another respondent praised the training he received because it helped him to value himself as a human being.

A number of participants said that although the training they received covered a variety of topics, very few courses were tailored to the specific needs of the trainees. For example, some male respondents with physical disabilities reported that they received training on disaster management, legal rights and HIV/AIDS, which was not their immediate priority, while training on general health and access to healthcare services was not covered:

"We need training on health issues to know how to keep ourselves safe from diseases, when we should go to hospital, and where the hospitals are."

A number of participants said that the application of the newly acquired skills was difficult because there were no jobs available for people with disabilities, and there was no start-up capital to open a business. For example, one female respondent with a visual disability reported that she had received training on business planning, which she could apply to start a small business, such as a bakery or a mobile (flexiload) business. However, she had no money to start her business and no organisation provided her with an advice on how to access the start-up capital. As a result, she perceived her training to be useless. A male respondent who received training on catering and weaving from VTCB and BVIPS reported that he could not start any business for the same reason. Three other male respondents raised similar concerns. They received between one and five days of training on stitching, packaging, leadership, and legal rights but they could not apply any of their skills due to the lack of capital and social support required to start up a business. Although all participants said that they could apply for a loan, the process of getting a loan was difficult and disability unfriendly.

Conclusion

This was a qualitative study, which included 33 people with disabilities and 13 stakeholders representing health providers, government officials and NGOs. The study provided interesting insights into experiences of disability, social participation and access to services, as perceived by people of disabilities themselves and their families. Evidence suggests that Bangladesh has a range of policies and provisions for people with disabilities but there is a gap between policy formation and policy implementation.

Study participants pointed out that many impairments leading to disability in Bangladesh are acquired in early childhood, often due to poor knowledge of where to get care, poor access to services and use of traditional remedies, particularly in rural areas. Disability is often associated with blame, guilt and misfortune. Stigma and discrimination of people with disabilities were also common in the studied communities. Women with disabilities are more likely to experience stigma than their male counterparts and they are more vulnerable to abuse and neglect in their communities.

Family was reported to be a critical source of support for people with disabilities. Close proximity of family members ensures safety and security for people with disabilities, irrespective of their sex, age or type of disability. However, in some cases, the relationship with family members, particularly siblings, are complex and there was reported evidence of stigma and discrimination within the families of people with disabilities.

Access to education was identified as a key priority for people with disabilities. The Government of Bangladesh has provisions for stipends for students with disabilities and there is a quota system for people with disabilities in higher education. But the study findings suggest that in practice, there is a lack of adequate infrastructure, educational materials and staff trained on disability in mainstream schools, particularly in rural areas, limiting opportunities of quality education only to those students who can access expensive special schools located in urban centers. Transition to higher education and employment was also reported to be a challenge.

Employment and sustainable livelihoods are also a critical issue for people with disabilities. However, opportunities for regular paid jobs for people with disabilities are limited and accessible primarily to those with higher levels of education. As a result, many people with disabilities feel that they are economic burdens and social liabilities to their families and frequently experience embarrassment and shame. Those who try to earn through petty trade or begging often experience ill-treatment and abuse.

The study further suggests that there are many formal provisions including different types of safety nets for people with disability in Bangladesh. Examples include disability allowances and stipends, policy for mandatory enrolment of students with disabilities to schools, employment quota in the public sector, provision of interest free loans and discounted transport fares. However, the findings also show that many people with disabilities are unaware of the existing legislation, the process of confirming eligibility for disability entitlements is complex and the resources allocated to the implementation of the existing legal frameworks are insufficient to cover all provisions for all people with disabilities.

Both NGOs and government institutions organise various types of training for people with disabilities. These cover both general awareness of disability rights and specific employment and business skills. Although these training sessions are generally well received and appreciated by people with disabilities, they are not always tailored to the needs and aspirations of specific groups of trainees. Application of newly acquired employment skills is also difficult, as the number of jobs available to people with disabilities is limited and many do not have any capital to start up their own business.

The study has a number of policy and programme implications:

Stigma and awareness raising activities:

- There is a need for further investment in awareness raising activities on disability and disability rights through families, community groups, service providers and mass media. The campaigns should target the general public, different stakeholder groups and people with disabilities themselves.
- Awareness of disability rights, existing policies and legal provisions should be built alongside clear mechanisms for holding decision-makers and service providers accountable for policy implementation. The role of Disabled People's Organisations (DPOs) is critical in exercising this accountability. Cases of disability-related discrimination (e.g. unlawful dismissals, violation of entitlements) should be systematically monitored and reported through the government and media reporting systems.
- All campaigns should be appropriately designed with clearly stated target audiences and behaviour change goals that they aim to achieve. There is also a need for rigorous evaluations of awareness raising and behaviour change campaigns to generate evidence on whether they achieve their intended goals and which approaches work better, for who and in which settings.

Access to health care and assistive devices:

- There is a need to join efforts with the organisations working to improve general health systems in Bangladesh, particularly in rural and deprived communities. It is critical to ensure that the general health systems in such locations have basic provisions to address common illnesses and accidents, which, if untreated, may lead to severe disabilities. Education of the general public and work with traditional healers is also critical to prevent inappropriate and harmful practices.
- Inclusive health approaches in general health facilities, including accessible premises and infrastructure, more appropriate working hours and positive attitudes of staff should be promoted and supported. Accessibility interventions should focus on different population groups, who may be at risk of exclusion, particularly women, children and older people with disabilities.
- There a need for a systematic assessment of assistive devices available to people with disabilities in Bangladesh alongside their prices, regulations, procurement and supply chain systems. Any improvements in the provision of assistive devices should include provisions for training and systems for maintenance and repairs. Initiatives to provide

information and improve motivation to use assistive devices should be included in awareness raising campaigns.

- Special schemes to subsidise ultra-poor in accessing health care and assistive devices should be developed and tested.

Access to formal education:

- There is a need for a systematic review of the current educational provisions for people with disabilities and how they work in practice. As part of this review, it is important to assess to what extent inclusive education is being currently supported in the education sector plan and education budgets.
- There is also a need for comprehensive data on the current levels of inclusion of children with disabilities in schools and their academic outcomes. Such data could be generated through national population-based surveys and national education assessments disaggregated by disability.
- There is also a need for national and regional plans on how to improve enrolment and participation of children with disabilities in education at scale, and specifically identification and assessment of children with disabilities, accessible school infrastructure, educational support and teacher training, procurement of specialist educational materials, educational assessments and family and home support.

Employment, livelihoods and skills training for people with disabilities:

- There is a need for a systematic review of the current employment provisions for people with disabilities (e.g. public sector quotas) and how they work in practice.
- Bespoke skills training programmes for people with disabilities should take into account individual characteristics of trainees, their aspirations as well as the contexts and labour markets, in which the newly acquired skills will be applied.
- Livelihood programmes focusing on the provision of equipment and tools should make provisions for maintenance and repairs.
- Employer schemes promoting and supporting access of people with disabilities to jobs should be piloted and rigorously evaluated to ensure learning from such schemes is widely disseminated and used.

Other social inclusion measures:

- There is a need for a review of the system of the provision of disability cards to ensure that the process is transparent and clear to people with disabilities and that all who are entitled to have a card can access it. DPOs should be considered as local intermediaries facilitating this process.
- There is a need for a review of the subsidised transport system, how it works and what the bottlenecks in the implementation are. This should be followed by specific recommendations on how the system can be improved, including raising awareness of the scheme among people with disabilities, developing systems to ensure the

entitlements work in practice (e.g. transport cards) and developing mechanisms of reimbursements to transport providers.

- There is also a need for more inclusive judicial practices, including systems of legal aid to people with disability (e.g. through DPOs) and disability inclusive courts and other legal institutions.

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