Snapshot

LEAVING NO ONE BEHIND

Is the health sector of Bangladesh failing to fulfil the needs of persons with disabilities?







Centre of Excellence for Gender, Sexual and Reproductive Health and Rights

BRAC James P. Grant School of Public Health (JPGSPH), BRAC University

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Table of Contents

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List of Acronyms

AAB	Action Aid Bangladesh
ADD	Action on Disability and Development
BBS	Bangladesh Bureau of Statistics
BLAST	Bangladesh Legal Aid and Services Trust
BODA	Bangladesh Organization for Disabled Advancement
CDD	Centre for Disability in Development
CRP	Centre for the Rehabilitation of the Paralyzed
CRPD	Commission for the Rights of Persons with Disability
DPO	Disabled persons' organization
DGHS	Directorate General of Health Services
FGD	Focus group discussion
HI	Handicap International
HIES	Household Income and Expenditure Survey
ICF	International Classification of Functioning, Disability and Health
IDI	In Depth Interview
INGO	International Non-Governmental Organization
IRB	Institutional Review Board
JPUF	Jatiyo Protibondhi Unnayan Foundation
KII	Key Informant Interview
NDD trust	Neuro-Developmental Disability Protection Trust
NFOWD	National Forum of Organizations Working with the Disabled
NGO	Non-Governmental Organization
NITOR	National Institute of Traumatology & Orthopaedic Rehabilitation
RIHD	Rehabilitation Institute and Hospital for the Disabled
SDG	Sustainable Developmental Goal
SES	Socio Economic Status
VASD	Village Association for Social Development
WHO	World Health Organization

Background

The understanding about disability is changing over time. The term, 'disability' itself highlights lack of ability, a definition which is slowly changing. In an article published in the Lancet, Leonardi (2006) proposes an alternate definition to the UN Convention definition and shows that in a 'bio-psycho-social' model disability has been described as an 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). According to Sherry (2008), disability is described beyond impairment. Rather than focusing on how disability results in impairment, the cultural, environmental or institutional barriers are also considered in discussions of disability. But these distinctions barely exist in the South Asian context.

According to WHO (2011), around 15% of the global population suffers from some form of disability, and 2-4% experience significant functional impairment. Global Burden of Disease data (WHO, 2004) shows similar finding, which indicates 15.3% of the world population (some 978 million people of the estimated 6.4 billion) have moderate or severe disability, while 2.9% or about 185 million experienced severe disability. In stark contrast to this data, in Bangladesh the official prevalence of disability is estimated to be 1.41% (BBS, 2012). However, Household Income and Expenditure Survey (HIES), 2010 estimated it to be 9.01%. Similarly, World Bank data reported prevalence in Bangladesh to be 14% among population aged > 18 (World Bank, 2004) and, prevalence based on gender was reported to be almost 9% among males and almost 11% among females (Tareque, Begum & Saito., 2014). Worldwide disability varies according to socio-economic and personal factors like age, gender, education and so on. At the global level, the Global Burden of Disease estimates of moderate and severe disability prevalence is 11% higher for females than males, (WHO, 2004), whereas the World Health Survey (2004) estimates give a female prevalence of overall disability nearly 60% higher than that for males. World Health Survey (2004) also reports disability rates to be ranging from 11.8% in higher income countries to 18.0% in lower income countries.

Persons with disabilities are at a huge disadvantage compared to rest of the global population. The majority of studies on this marginalized group of population find that, persons with disabilities (PWD) have less health care utilization, lower employment rates, lower educational attainment than persons without disability (Trani & Loeb, 2012; Mitra, Posarac & Vick, 2011; Eide & Kamaleri, 2009; Mete, 2008; Loeb et.al., 2008;Mitra & Sambamoorthi, 2008; O'Keefe, 2007). An analysis of the World Health Survey (2004) data for 15 developing countries suggests that households with disabled members spend relatively more on health care than households without disabled members and persons with disabilities demonstrate a strong need for better access to health care services (55.3%), medications (21.3%), technical devices (17.5%), and financial help for basic needs (52.5%). In Bangladesh, formal health care utilization among persons with disabilities was reported to be quite low, and in rural areas in 81% cases, consultation was sought from informal sector (Razzaque, Nahar, Akter, Khanam, & Streatfield, 2010; Hosain& Chatterjee, 1998). Health care facilities including community clinics, Upazila Health Complexes and district hospitals, generally lack provisions for accessibility and providers' expertise required for early

identification of disability, handling patients with disability, early intervention, counselling and rehabilitation (BLAST, 2015). There are obvious healthcare needs of persons with disabilities, however, the lack of quality of care, appropriateness services and responsiveness of providers result in underutilization of services (Lawthers, Pransky, & Himmelstein, 2003). Medical professionals generally lack knowledge on how to provide services to women with disabilities when they become pregnant, including pre-natal, natal and post-natal care (BLAST, 2015; World Bank and PROB, 2015). Existing barriers to access transportation, especially public transportation, further complicates accessibility to health care for persons with disabilities (BLAST, 2015; World Bank and PROB, 2015). In a survey done by BLAST (2015), 52 % of the respondents said that Government hospitals do not provide medicine or treatments for free for persons with disabilities who are poor, although the Ministry has issued rules in accordance with the Rights and Protection of Persons with Disabilities Act 2013, stating that this should be the case; the same survey also reported, women with disabilities were particularly vulnerable to discrimination, violence and injustice (BLAST, 2015).

In order to address the special needs of persons with disabilities, on 13th December 2006 the United Nations General Assembly formally adopted the Convention on the Rights of Persons with Disabilities (CRPD), the first human rights treaty advocating for the rights of persons with disabilities. Bangladesh became a ratifying state party to the CRPD on 30 November 2007 (BLAST, 2015; WHO, 2004). Prior to this, the only national law dealing with disability issues was the Bangladesh Persons with Disabilities Welfare Act, 2001. Existing policies include the National Policy on Disability 1995 and the National Action Plan on Disability 2006 (BLAST, 2015).

Many NGOs and INGOs are working for persons with disabilities in Bangladesh, such as Handicap International (HI), the National Forum of Organizations Working with the Disabled (NFOWD), the Centre for the Rehabilitation of the Paralyzed (CRP), Centre for Disability in Development (CDD), Action on Disability and Development (ADD) Bangladesh, Rehabilitation Institute and Hospital for the Disabled (RIHD), Training and Rehabilitation Centre for the Physically Disabled, Action Aid Bangladesh (AAB), Bangladesh Organization for Disabled Advancement(BODA) and so on; but their efforts seem to be able to reach only a very small proportion of the disabled population. Although these laws and policies are in place to preserve rights of PWDs by facilitating appropriate provisions by the Government, Health system and service providers, it is argued that inadequate implementation and enforcement, lack of drafting new and amending existing policies, lack of inter-ministerial collaboration, accountability, monitoring, supervision, effective utilization of budget often lead to the discriminations and barriers that PWDs have to face.

“LEAVING NO ONE BEHIND”

‘The Leaving No One Behind’ partnership was established in July 2016, and it is made-up of three international non-profit organizations (CIVICUS, Development Initiatives, and Project Everyone) with the support of the United Kingdom’s Department for International Development. It seeks to drive the global movement in order to achieve the SDG aim of ‘no one left behind’ by 2030, for all marginalized groups, including persons with disabilities (PWDs). Persons with disabilities seem to be the worst victims of exclusion, and the

developed and developing countries are poorly performing according to set indicators; and, Bangladesh is no exception (Field, 2000).

Their experience differs by socio economic condition and environment, but their living condition and barriers in accessing health care remains the same (Kowel et al, 2010).

The 2030 SDG aims at mainstreaming all, irrespective of age, sex, disability, race, ethnicity, origin, religion, economic or any other status (Griggs et al., 2013). The aim of the inclusion is not only for setting agenda or indicators, rather it aspires to know whether development process is being inclusive or not, particularly paying attention between exclusion, poverty and employment trends. Indicators have been set to measure access to opportunities such as education, health and other basic services to measure participation in political, civic and cultural affairs (WHO, 2016). The inclusion is not only ensuring that policies be in place, rather it aims at putting organizations and agencies in action to recommend activities that government can take into account in order to avoid exclusion of marginalized groups.

Justification of undertaking the study

To reach the set goals of SDG by 2030 where Bangladesh is a signatory to ensure 'no one is left behind', it is important to situate PWDs and issues related to disability in the national mainstream so any efforts towards improving their conditions may reach the larger population of persons with disabilities. A diverse group of population in covered under the disability term where everyone matters, irrespective of their age, gender, socio-economic condition and religious background. Unfortunately, despite there being a mandate by the government to make the public and private sphere inclusive for all, this group of population has always been neglected and marginalized. As a result, they are lagging behind in their basic rights like education, employment and especially in health care. The severity of the situation worsens when it comes to socio economic background, gender, ethnicity, empowerment, education or even living conditions. It can be safely stipulated that when 15 % of the population are lagging behind, it is a clear threat for any nation like Bangladesh. To ensure the rights of this specific group of population, government has undertaken a lot of appreciative initiatives, however, it is extremely important to look at how the health system is performing to ensure health services to them. Despite such efforts, there is still not enough comprehensive data and original research on persons with disabilities in Bangladesh to inform advocacy and policies. This study commissioned by BRAC Advocacy for Social Change to BRAC James P. Grant School of Public Health, BRAC University, undertook a qualitative exploratory study on the system barriers and challenges that exist and impede accessibility and utilization of health care services by persons with disabilities. The research study will contribute some initial findings directed towards policy makers, Government and non-government implementers and relevant stakeholders. The evidence will add value to existing

knowledge and inform advocacy strategies for improving overall health care of persons with disabilities considering the different types of disability, personal and macro social, political and economic factors.

Objectives

The study was undertaken to explore whether the health sector of Bangladesh is failing to fulfil the needs of persons with disabilities, and if so, why. To achieve this larger objective, three specific objectives were set in discussions with BRAC. The first specific objective was to explore the 'unmet' needs of persons with disabilities and their experiences of accessibility, availability, and utilization of health care services in Bangladesh. Through this objective, the study aimed to explore the effect of disability on these individuals' lives and the challenges they face when seeking health care.

The second specific objective aimed to explore the existing barriers in availing health care to fulfil health needs, as faced by persons with disabilities in Bangladesh. Through this, the existing barriers to availability, accessibility, utilization of health care services by persons with disabilities, and the reasons underlying these barriers (infrastructure, distance, cost, quality of care etc.) were explored.

The third objective aimed to explore the system related macro-level challenges contributing to barriers in fulfilling health care needs by persons with disabilities in Bangladesh. Challenges in policy and its implementation, budget allocation, human resources, coordination among implementing ministries of the government, monitoring and supervision, etc. were explored to achieve this objective.

The study population

One of the key study populations was persons with physical disabilities. The physical disability ranged from restricted movement of any limb to partial to complete paralysis, i.e. physical disability of varying degree. The disability could be due to any cause- injury, infections, genetic disorder, birth complications, to stroke. The participants included in the study were all above 18 years of age.

It did not include persons with intellectual impairment or sensory impairment, due to ethical issues in accessing those who were mentally challenged and the right to make informed consent, time and resource constraints. To include them would also require different methods (data collectors trained in sign language/trained to have conversations with persons with intellectual impairments), screening (using multiple validated screening tools for such kinds of impairment including clinical tests for sensory impairment) would have been required, which was not feasible. It would also have required interviewing not only these stakeholders, but also representatives from multiple other implementing agencies of government, INGO and NGO who deal with intellectual and sensory impaired persons,

making the study population much larger. Given the ethical challenges and time limitations of this research, it would have been very difficult to attain good comprehensive data.

Other study populations included:

- INGO, NGO, and DPO (Disabled persons' organization) stakeholders
- Implementers of Government programs at:
    - Ministry of Social Welfare
    - Ministry of Health & Family Welfare
    - Community Based Health Care Wing of Directorate General of Health Services (DGHS)
    - Hospital Wing, DGHS
    - NITOR (National Institute of Traumatology & Orthopaedic Rehabilitation)
    - Autism Cell
    - Jatiyo Protibondhi Unnoyon Foundation (JPUF)
- Health-care provider, Dhaka Medical College Hospital

Methods

An exploratory qualitative method was adopted to explore and understand the 'unmet' needs of persons with disabilities and barriers that they face while availing health care and services from facilities. The duration of the study was from April to June 2018 (three months). To address the objectives in a comprehensive manner, data was collected from multiple groups of population (persons with disabilities, stakeholders, government representatives) using several methods of data collection. This ensured triangulation of data and validity to data collected.

To address specific objectives 1 and 2, four in depth interviews (IDIs) and three focused group discussions (FGDs) among a total of twenty persons with disabilities, were conducted. Among the FGDs, one was conducted in a mixed group (male-female), and one only among males, and one only among females. Among the four IDIs, two were male and two were female respondents.

Table: Study population, sample and data collection tools

Study Population	**Data Collection Methods**	**Data Collection Tools**	**Number of Respondents**
Persons with disabilities	In-Depth Interviews (IDIs)	IDI Guideline	4 (2 male, 2 female)
	Focus Group Discussions (FGDs)	FGD Guideline	3 (total 20 participants)
INGO, NGO, DPO stakeholders	Stakeholder Workshop	Open discussion, interactive group work	13
Health Care Provider (Govt.)	Key-Informant Interview (KII)	KII Guideline	1
Govt. and NGO Representatives	KIIs	KII Guideline	8

The respondent groups included respondents with age ranging from 20 years to 52 years old and varying degrees of disability ranging from leg deformity due to polio to loss of hand to quadriplegia (paralysis of all four limbs). Most of the male respondents from VASD had small businesses or were shopkeepers; three of them did not have any income source. The respondents (male and female) from CRP were admitted into the vocational skills training centres. The female respondents (CRP and VASD) in the study did not have any income source. Selection of respondents was through convenient sampling; each group contained about 6-7 participants in the FGDs. Respondents were accessed through support from the Centre for Rehabilitation of the Paralyzed (CRP), Savar and Village Association for Social Development (VASD), Savar. The interviews were conducted in disability friendly spaces (CRP, VASD premise) and respondents' residences so that they could open up and speak frankly about the barriers faced, both personal, social and institutional. Interviews were taken in privacy, to ensure that service providers or family members could not interfere or bias the responses.

To understand the micro (barriers faced by persons with disabilities when they go for health care) and macro level system barriers (policy level to health system levels), discussions with INGO, NGO and DPO stakeholders (program/intervention implementers) took place. As part of the research methodology, a Stakeholder Workshop, took place, which was half a day and interactive. This was held at BRAC JPGSPH premises. Thirteen stakeholders from selected INGO-NGO-DPOs attended the workshop and participated in the discussions and facilitated group exercises to elicit responses. The relevant stakeholders participated in discussions facilitated by guidelines which were prepared based on objectives of the research and additional themes as highlighted by a literature review done on existing reports, primary studies and articles in the Bangladesh context. The stakeholders were purposively selected and identified through BRAC Advocacy team's contacts for the advocacy platform for disability issues. The information generated from this workshop was noted down, recorded and the data was analysed for the study. A key informant interview (KII) of health care provider from a tertiary level Government Hospital was also conducted.

Key informant interviews (KIIs) with Government health system representatives (mentioned in the 'Study Population' section) were conducted to explore the macro-level barriers. Respondents were selected purposively based on if they were viewed as the best positioned and most relevant in answering queries around health care and PWD issues in the Government system.

In-depth interview guidelines and FGD guidelines, were pretested and modified accordingly - WHERE, were used to conduct the interviews. KII guidelines were pretested within the team, as is customary, to modify and finalize before employing in the field.

Photo: Group work during stakeholder workshop for NGO, INGO, DPOs

Data Collection Process

Data collection was done by dividing into two/three pairs to conduct KII, IDI and FGD simultaneously within a short time. For the KIIs, the respondents were contacted to get an appointment for interview. On the scheduled date and time, two researchers went to interview, where one took the interview and the other took notes. This was done as the government representatives were reluctant to record the interviews.

Before the IDIs and FGDs, the team visited the study sites, CRP and VASD to gather ideas about the possible respondents and the site for feasible locations to conduct interviews. The CRP and VASD staff helped arrange the FGDs in the premises, and also helped contacting respondents for IDIs. At CRP, the respondents were contacted at the hostel and training centers within CRP with help from CRP staff, their contact number was collected, and interviews were scheduled according to their given time at their residences and at CRP. VASD helped contact respondents for IDIs and helped reaching their homes for the interviews. These interviews were also done after contacting with respondents and scheduling a suitable time.

On the days of fieldwork in Savar, the research team spent all day conducting interviews. Due to the short time of fieldwork, the team was split in twos; while two people conducted one IDI, other two conducted another IDI. Two or three members conducted each FGD; two were held consecutively in one day, and one on the next day. IDIs were scheduled in the weekends to facilitate the presence of the whole team in Savar for the day, and to avoid overlaps with KIIs. KIIs had to be scheduled in the weekdays, as the government staff were reached at their offices. The KII schedules often overlapped, and in the cases two researchers interviewed one Key informant, while other two interviewed another respondent.

Ethical Considerations

Field work was interrupted for more than a week (12th-19th June) over the Shab-E-Qadar and Eid-Ul-Fitr holidays, as the Ministries, CRP, VASD and hospitals were all closed. Some of the government respondents were on long tours abroad and could not be reached until the last week of June.

The study was given ethical clearance by the Internal Review Board (IRB) of BRAC James P. Grant School of Public Health. Formal permission letter was collected from CRP and from DGHS, after sharing the concept notes and IRB certificate, before proceeding with data collection. Informed consent was collected from all respondents. Many of the respondents in FGD, and Govt. KIIs did not wish to sign the form, and in their case, verbal consent was collected. Permission was taken before recording, taking notes and taking any pictures. The IDIs and FGDs of PWDs were all recorded using tape recorders. All but one government representative refused to be recorded, and therefore notes were taken during interviews, and were immediately converted into detailed descriptions after the interviews on the day.

The discussion from the Stakeholder Workshop was recorded using tape recorder, notes were taken, and the flipcharts where participants wrote during group work were collected as part of the data collection process.

Identifying information of participants in the study was removed from transcripts and notes, and names were replaced with ID number, before analysis as per procedures of ethical consent. The raw data (recordings, transcripts, notes) were stored in the JPGSPH server which is password protected, and only accessible to researchers who are part of the research study.

The researchers left their contact number and contacts for IRB Board which gave ethical clearance of the study, with the respondents, should they have any queries.

Data Analysis

Data analysis (initial) started as soon as the first interview transcript was done and continued simultaneously with data collection. The final analysis was done after all data was transcribed, coded and entered into data matrices.

The collected data was transcribed verbatim, translated and then coded using a pre-generated code-book. Notes from KIIs and all FGDs were coded as well. Along with the deductive codes, new codes identified from data were included in the code book as inductive codes, and the transcripts and notes were again coded accordingly. A data matrix was generated, in which data was segregated into the themes. Analysis was done within and between themes, and identified patterns were reported as findings.

Validity and quality of coded data was maintained by inter-coder reliability checks. Every code and related data inserted into code book and matrix was cross-checked through discussion within team members and only put there after there was a consensus among the team. Supervision and random checks of transcripts, coding and analysis and discussion of findings took place by Senior Advisors, to ensure quality.

Findings and discussion

The findings of the study are described under three sections. In the first section, we discuss the experiences of persons with disabilities and how disability affects them at a personal and emotional level, and the socio-cultural and economic impact disability also has on their lives. Overall, the findings found that lack of education and employment opportunities perpetuate poverty among persons with disabilities. However, it is a continuous vicious cycle because if they are poor, they face even more difficulties in accessing education and therefore opportunities for jobs. In general, irrespective of social class and status, most persons with disabilities face social stigma in the community, from neighbors, and often in the family. But this becomes even more severe if their economic condition is poor. The social stigma, limited income opportunities and sense of being a constant burden on family due to

movement restrictions, has negative psychological impacts, such as depression and low self-esteem. Women, being more dependent financially and for decision-making on husbands and family members, were found to be more neglected and affected psychologically. They suffer more from social stigma when it comes to marriage, pregnancy and child rearing. The widespread perception is that they are not marriageable, can't bear healthy children and will not be able to take care of husbands and children like a 'normal' person. For persons with disabilities from higher socio-economic backgrounds, hiring assistance and assistive devices were easier, and better affordability got them better quality of care. However, the stigma often persisted of viewing them as less than an able bodied person.

In the second section of the report, we discuss barriers to health care services as faced by persons living with disabilities. The overall findings suggest that inaccessible infrastructure in health facilities and inaccessible public transportation to be major barriers in health service uptake by persons with disabilities. Lack of knowledge, skills and sensitivity of health care providers in facilities also resulted in underutilization of services. In the final section of the report we focus on the macro-level challenges and barriers found in policy and implementation, i.e., resource allocation, ministerial coordination, monitoring and supervision, etc. These macro level challenges continue to contribute to barriers existing in the community level by hindering implementation of policies at the community level. All the sections will be discussed in more details below.

A. Experiences of Persons with disabilities: How disability affects them?

Feeling like a burden on their family

The research found that depending on the severity of the disability, persons with disabilities have varying degrees of restricted movement which affect their everyday life, level independence and thereby, produces certain psychological and emotional effects on the individual. The participants had varying degrees of disability ranging from disability by birth, loss of one hand due to injury, to loss of movement of whole body from neck down due to severe spinal cord injury. The personal experiences of four persons with disabilities were explored through IDIs, and three FGDs, which gave insights into the general experiences of persons with disabilities.

It was found that, individuals who had more restricted movement required more assistance from family members to go about their everyday lives. All the activities that an able-bodied person can do, such as, cooking, feeding, cleaning oneself, dressing and moving about, etc. are quite time-consuming and difficult for persons with disabilities; and often impossible to do alone in the case of a severe disability. Being constantly dependent on and taken care of by family members in their daily lives, they develop a sense of being a burden on the family which leads to having low self-esteem.

The research found that, men with disabilities felt they were a burden even more, when they were not able to earn and provide for the family. This was re-enforced by the negative attitudes of family members, who did not take kindly to the individual when he was not contributing to the family income. One respondent, a 46 year old male with one amputated leg from peri urban Savar expressed his sadness saying, *"I am disabled, my wife and*

children do not care about me….when I earn and give them the money at the end of the month, they think I still have value, and they provide the help I need doing my daily work.

Last month I fell sick, I could not go to work, and I had no money….I was lying helpless in bed, I requested them to take me to the doctor as my leg was hurting a lot, but they did not listen to me. My wife said, let him be, we'll see in the morning….she does not value me anymore as I am not 'normal'"

Women with disabilities who were married, felt that they were a huge burden by the in-laws family if they were not able to bear children; and again this feeling was re-enforced by negative attitudes of family members. Women who were unmarried, felt they were quite a burden on parents as they cannot get married. This was enforced by social stigma shown by neighbors, community and sometimes the parents themselves.

"My womb is barren because of my condition, now that they (in-laws) know it, they don't care about me at all. My husband and in-laws do not listen to me when I need something, they do things as they wish….I do not feel like asking them for any help, even when I am sick….I can tell they are frustrated and do not want to spend time on me anymore…A woman's most special organ is in the womb, if you don't have a fertile womb, you have nothing"- Female, 32 years old, paralyzed from waist down, from peri urban Savar

Poverty, limited opportunities for education and employment and health care behaviour: The vicious cycle

In general, in the IDIs and FGDs, there was general concerns shared as to the lack of provisions in the education and occupation sector. This was a vicious cycle with poverty, leading to not being able to study and or a lack of education leading to limited job opportunities with little scope of earning a stable decent income, which led to poverty. Poverty again resulted in limiting what was available, affordable and the ability to buy assistive devices and paying for treatment and services. Poverty also made persons with disabilities more vulnerable to social discrimination and stigma, which negatively affected their ability to access education, occupations and health seeking behavior.

According to respondents in IDI and FGDs, both with persons with disabilities and stakeholders, disability itself is found to lead to very few jobs available or losing a job. When individuals could no longer carry out the functions because of their disability, they were fired. Individuals who have the disabling condition from birth or early in life, find it very difficult to find a job as most of the jobs require physical exertion which is not possible by them. The more severe the form of disability, the less opportunities of income exists, especially if it requires physical exertion. For better paying jobs with less physical exertion, a good educational background is needed and social networks, which many persons with disabilities from poorer families are not able attain. Sometimes families do not want to continue education of family members with disabilities because of stigma and social shame and they don't see any future or opportunities, rather it is a drain on the limited money the family has.

"They are not able to study and compete in schools like others, they need special aid and infrastructure to help them continue studies, which is not available…In one case, we have had the girl's family stop her from going to school, although this family was rich, they were

still ashamed to send their daughter to school because of all the comments other students and parents made"- DPO representative, in Stakeholder Workshop

Case Story: Hossain (27, male) paralyzed from waist down

The experience that Hossain has had which led to him becoming physically disabled is every immigrant worker's nightmare come true. While working in Saudi Arabia since 2007, his fate took an unfortunate turn on 6th September 2013 when a billboard fell on him and damaged his spinal cord. Unable to access any healthcare services after the accident as he was an undocumented worker, Hossain had to bear the pain till he was sent to fly back to Bangladesh on 13th September. Immediately after coming back to the country his family took him to the Trauma Center where he underwent surgery to fix his spinal cord injury. During this time his lungs filled with blood and his medical condition deteriorated, with doctors confirming that he would be paralyzed from waist down for life. If this news wasn't traumatizing enough, Hossain also had to deal with medical expenses as money was running out and it was running out fast. As per the suggestion of his doctors, he then shifted to CRP for getting physiotherapy. Financial troubles followed him there too, and after staying at CRP for about one and a half month he had to get discharged as he couldn't afford their services anymore. Since then life hasn't been too kind to him. His mother had to leave him and go to Saudi Arabia to work and send money home, his elder sister had to discontinue her education to take care of him. For both the cases, Hossain keeps constantly blaming himself. With another younger sister still in school and him being unable to work, Hossain's only wish now is to find a job appropriate for his unemployed old father. Elaborating on an incident where he suffered from bed sores and resulting infections, he said he had requested his uncle to send him some money for treatment, and he recalls sadly how his uncle told him that it would have been better for both him and his family if he would have died in the accident rather than being a burden on his family.

Photo: One of the in-depth interview respondents in conversation with our research team members

Stigma: External and Internal

Persons with disabilities are often stigmatized by the neighborhood and community they live in, as well as by the larger society. In the in-depth interviews, the respondents, male and female alike, talked about their experiences of being stigmatized by the people around them. They are called names, such as *'Langra'* (lame male)/ *'Lengri'* (lame female), '*Pongu'* (disabled) etc. by the neighbors they know as well as others they do not know in the community, when they go out. People frequently stare and comment on their condition when they are in a public place or travelling. Two of the respondents mentioned being pointed at in the streets by people they did not know while they called them out using such names. These incidences were also reported to happen more in villages than in the urban areas. One respondent, female, 18 years old, who did not have a left hand, from peri-urban Savar,expressed her anger:

'It is nothing to do with my deformity, it is how people view me. I do not have my left hand, but I have both my legs. Yet people in the street calls me 'Lengri' (lame). Why do they call me that? I do not understand...'

There appears to be a general understanding in Bangladesh that persons with disabilities are not 'normal' or 'less than', 'defective' in some way, and or they are helpless and incapable of performing activities like an able-bodied person. The general perception is that they require constant care and create an economic burden on their families. Often times the disability is blamed on them as if it is their fault, are 'cursed' or paying for a 'sin' committed by the affected individual or the family. Since persons with disabilities are not capable of studying and earning like a 'normal' 'capable' person, and particularly in poor families, there are few options and families have to bear the responsibility throughout their life. These prevailing realities and embedded ideas of the lack of worth of a person with a disability, results in stigma and negative attitudes among family, relatives and within the community. Society constantly associates disability with a curse, a financial burden and shame on a family, and even family members look down upon the family members who have disabilities. The family and parents, who take care of them, and the persons with disabilities themselves, constantly have to listen to such remarks from relatives and neighbors.

"I hate the sympathetic people who talk about me (in the neighborhood)….what kind of sympathy is that? They tell my parents how unfortunate they are to have a daughter with one leg. They say, I am 'meyejaat' (female), how would I ever get married? I cannot earn, I cannot do my own work….they say I am a constant burden on my family which they will have to drag on for the rest of their lives, it is so sad….what kind of sympathy is that?"- Female, 28 years, lost one leg after an accident, from urban Savar

Persons with disabilities are generally deemed not eligible for married life and suffer a lot of negative perceptions when it comes to being marriageable This was irrespective of gender as both male and female persons with disabilities, no matter what the form of disability, were seen as unattractive, not desirable as they lacked the muscular body frame of a strong male and therefore considered weak and not manly and viewed as incapable of sexually satisfying their partners. The common perception was that males with disabilities cannot earn as much and sustain a family like an able-bodied man, and therefore are not seen as good marriage

prospects. Males are viewed as the primary rice winners of the family and therefore, a disability automatically disqualified them.

"They (relatives) had said to my wife, he is disabled, he will not be able to earn much in his life. How will you be able to have a good life with him?"- Male, 45 years, paralyzed from waist down, from peri urban Savar

Female persons with disabilities require taking care of, rather than them taking care of in-laws, husband and children. As females areviewed socially to be the primary care giver in the family, they are immediately considered ineligible by virtue of their perceived disability, even if it is a minor disability. The social expectation is that a desirable female who usually needs to be able bodied and have 'functional reproductive organs' and body parts (uterus, vagina, breasts etc.), which means they would be eligible sexual partners and bear children in future. Females with disabilities are viewed as less than desirable to be sought after or marriageable material for a family.

"I like to go out and I want to wear saree like other girls. They look so pretty, boys stare at them. But I don't. I walk with a crutch. I will never be able to look as attractive as them in saree, I will never be able to carry myself the way they do. Boys never look at me when I am out with other girls. They don't find me beautiful"- Female, 22 years, one leg is crippled, from peri urban Savar

The respondents shared that there was wide spread superstition that a female with a disability cannot bear children, or if they can, the child is not going to be healthy. All these stigma and superstition creates obstacles in having a happy, married life. The research found, although the male persons with disabilities from better off families are often married off by parents with the girl from a less well-to-do family who is expected to take care of him. In contrast, females have real difficulties in finding a husband. The relatives and neighbors often discourage parents against it, or parents themselves do not look for husbands, and generally formal proposals are not sent for marriage. In one case, where the respondent (IDI) did fall in love and she shared how she was constantly stigmatized and taunted by her in-laws and neighbours for a very long time whether she would ever be able to bear and properly take care of a child. She said-

"*They had no choice because their son was stubborn. But even 10 years into the marriage, I can tell, they (in-laws) haven't accepted me from their heart…My mother-in-law used to say you are crippled, you will not bear a healthy child if you are able to bear children at all. She said, how could I be such a bad person, that I could not see I was ruining her son's life"*- Female, 32 years old, paralyzed from waist down, from peri urban Savar.

Case Story: Sefali (32, female) paralyzed from waist down

"I am less than you...this is the attitude [of others]…if you are using wheel chair you are not beautiful... [We] are a burden…."

After reading about Sefali's experiences, one cannot help but be surprised at her sheer resilience and strength. From the age of 5, Sefali was prone to falling down a lot and would often limp. Community members around her started calling her *"lengri"* (crippled/lame), her friends would be hesitant to walk to school with her as she often used to fall down and get her clothes dirty. Ashamed of being associated with her, friends and neighbours stopped communicating with her and her elder brother became her only companion. Unable to stand the continuous taunts of her family, neighbours and peers alike, Sefali's mother left no stone unturned in her daughter's treatment. Her (Sefali's mother's) first point of contact for primary health care for her daughter were kobiraj (traditional healer). Starting from drinking sandalwood with milk to standing for hours in broad daylight with a mixture of lemon salt rubbed on her legs, four different kobirajs' subjected Sefali to different levels of torture.

At the age of 10, Sefali was finally diagnosed with a spinal tumor which was believed to be the cause of her limp. Sefali's mother took her daughter to PG hospital with the hope that removal of the spinal cord tumor would make her daughter healthy again. However, after waiting for an appointment for more than two months, she decided to have the surgery under a doctor who promised to operate on her free of charge. Seeing this opportunity as a blessing, Sefali unwittingly became a guinea pig in the doctor's experimental surgery on her tumor, resulting in her disability from the waist down. It was the failure of this tumor removal surgery which led to her paralysis from the waist down.

Since then, life has not been kind to Sefali. If her disability was not enough to cause her unbearable pain and suffering, she was also diagnosed with diabetes which made her more prone to getting infections even due to a minor cut or scrape. Despite such hardships, Sefali studied and passed higher secondary curriculum examination. She only went to school to give exams as her peer circle had completely isolated her at that point. Not only that, she also engaged in a love affair and got married to the man of her dreams. Unfortunately her in-laws didn't accept her and she also refused to spend her days in a home where no one respected her. Societal perceptions and expectations aside, Sefali's greatest regret is that no healthcare provider has been able to fully understand her medical condition. So far, she has had six miscarriages because her doctors failed to identify that her miscarriage was due to her high blood sugar and not a result of complications of her disability. Sefali laments the loss of her unborn children, as she feels that she was never looked upon as a normal person and always had to carry the disabled tag all her life.

"Despite facing obstacles in life as a disabled person, I was always strong-willed. However, with each miscarriage, I had a mental break down….but no one understood me…they (doctors) only questioned my want to have a child given my disability. They told me the miscarriages were a blessing in disguise…"

Sefali still feels blessed as due to her husband's unfailing support, her in-laws finally accepted her and she is now waiting with bated breath for her wedding ceremony which is scheduled to take place soon.

Emotional and mental health and well-being

Manifestation of the psychological consequences differs for male and female persons with disabilities. In the IDIs, males are found to be more concerned and pained by the fact that they are not capable of earning for the family, rather they are the reason of expenditures. Females usually think they are less capable of taking care of their families, husbands and children, and that they are not fulfilling the role of caregiver in the family properly.

For females who were not married, the thought that they will never get married and will be a burden on the parents without gaining any financial stability, is found to be the reason of low self-esteem. According to a female respondent, 32 years old, paralyzed from waist down after a tumor invaded her spinal cord when she was an adolescent, living in peri-urban Savar

Photo: One of our middle aged female focus group discussion participants who needs assistive devices in her daily life

'I had a love marriage that is why I could get married. Otherwise who would have married me? To them I am ugly, in a wheelchair….. A disabled man can easily marry an able women. No one wants to marry a lame girl.…'

Stigma, inability of have a good education and income, poverty, and sense of being a burden- these factors keep re-enforcing each other, impacting on the mental and emotional well-being of persons with disabilities.

The findings regarding existence of social stigma towards PWDs are echoed in findings from Bywaters, Fazil, Wallace and Singh (2003), Reeve (2002) and Keith & Dalley (1992), where the researchers report of negative attitude of 'normal' people towards PWDs, social stigmatization and un-acceptance of PWDs and their families, and the feeling of shame enforced by such stigma into the PWDs. Ahmmad & Islam (2012) and Titumir & Hossain (2005), in studies done in Bangladesh, report of existing social stigma towards persons with disabilities. It reports that, such individuals are considered burdens by the society, often family, and the condition is thought to be a curse. It also reports that persons with disabilities are considered not marriageable by others in the community

Studies done by Reeve (2002), North (1999) and Glass (1993) reported similarly that is there is internalized stigma, and a person with a disability often feels self-loathing, depression and pity on oneself because of their condition and their inability to carry out activities like 'able' bodied people. They also state that for conditions which are more severe, for example in spinal cord injury, the PWDs are thrust into a state of sudden shock, anxiety and depression as they try to adjust with their condition. Ahmad & Islam (2012), in a study done in Bangladesh, reported that, disability had a devastating effect on the quality of life of the disabled people with a particularly negative effect on their marriage, educational attainment, employment, and emotional state. Titumir & Hossain (2005) reports of existing social stigma towards persons with disabilities in Bangladesh. It reports that, such individuals are considered burdens by the society, often family, and the condition is thought to be a curse. It also reports that persons with disabilities are considered not marriageable by others in the community. All these have a negative effect on emotional wellbeing and quality of life of persons with disabilities.

Role of socio-economic background and family support

Analyzing the accounts of respondents (persons with disabilities) in IDIs, FGDs and the cases shared by stakeholders in the workshop, the research evidence found that usually persons with disabilities with high socioeconomic status (SES) or who come from an influential family background, can afford support and care and bring assistance for the family member with a disability. The person with the disability would be more often be treated with respect or at least not face taunts compared to those who came from poor families. Persons with disabilities who are rich themselves also have better accessibility and less dependency for seeking care.

However, irrespective of background, persons with disabilities are found to be often neglected and stigmatized by their families. It was also reported by stakeholders and persons with disabilities in IDIs, FGDs, that women, being more dependent in terms of money, assistance and even decision-making, are often neglected more by family members and they are more hesitant and reluctant to seek health care, therefore seek care less.

"The economic condition of my family is good but my father or brother is reluctant to spend more for me. I can't even ask for pocket money, since they already spend so much on medical bills….They get irritated if I need to visit the doctor frequently….I only tell about my illness when I can't tolerate anymore."- Female, 20 years old, paralyzed from waist down due to connective tissue disorder, from urban Savar

Without adequate support and encouragement from the family, it is rare that a person with a disability can progress much in terms of education, earning, even independently seeking care. This is also because of the lack of institutional support structures in place in Bangladesh.

In a survey by BLAST it was also reported that, women with disabilities were particularly vulnerable to discrimination, neglect, violence and injustice (BLAST, 2015). Ali (2014) in his study done in Bangladesh, reports of persons with disabilities having fewer options for employment and not being a part of the mainstream economic activities, even when the countries are progressing ahead in terms of economic growth. Persons with disabilities also require long-term, often life-long treatment and medication for their conditions. Disabilities

are often accompanied by co- morbidities and complications, and the health care cost for them is high and continuous. The study also reports, access to education of children with disabilities is very limited in Bangladesh, because of improper physical infrastructure, lack of proper training among the teachers, lack of appropriate teaching-learning materials and lack of assistive devices for both mobility and communications; all of these lead to high drop-out rates (which is discussed in more detail in the next section of the report). Diwakar (2017), also in a study done in Bangladesh, found disability and poverty to be interrelated; often poverty makes disability more disabling where unemployment of persons with disabilities makes them even poorer.

B. Barriers to Health Care Services

Absence of appropriate infrastructure in health care facilities

The interviews with persons with disabilities and FGDs found a common complaint, that majority of the health facilities are multi-storied and without provisions of ramps, and elevators were cramped, small doors which were inaccessible, particularly for those using assistive devices (wheelchairs, motorized wheelchairs, crutches etc.). The toilets in the facilities were not disability-friendly; they were not spacious with wide doors for wheelchair accommodation, did not have wheelchair-height commode, sink and grab bars to hold on to. This was the case in government primary and secondary health care facilities and in most private health care facilities. In instances where the provisions are there, in tertiary level facilities, the provisions are not adequate to meet the demands of the large number of individuals coming for treatment. In cases where ramps existed, it was reported by stakeholders that these ramps were not installed or built according to the appropriate measurements for the slope. Therefore, the slope did not allow wheelchairs to move up smoothly, rather made it difficult and made one prone to accidents.

"You will have a lot of difficulty if you try to climb up those ramps on a wheelchair. The measurement is not right and the slope is too steep. Often they are not wide enough. They also don't have railings which you can hold on to. Even individuals using crutches could fall off from these ramps" - NGO representative, in Stakeholder Workshop

Apart from physical infrastructures, the facilities have really long queues for getting an appointment with the doctor, which again poses problems, as standing for long hours in line is very difficult for persons with disabilities, especially for those who use crutches, artificial limbs, and do not have assistive devices such as wheelchairs. Also, it was reported that upon entry, although a person with disabilities should be provided with assistance by someone and with a wheelchair, if required, it was almost never available. One respondent in the stakeholder workshop said from her own experience,

'I could see that she (a person with an amputated leg) cannot stand so long on her crutches, and she was sitting in the middle of the line helplessly while people were passing her by, but no one from the hospital came forward offering a hand or a wheelchair' - NGO representative, Stakeholder Workshop

Persons with disabilities also report, that tertiary level facilities are quite distant from their homes, especially in rural and peri-urban areas, and therefore it is difficult for them to access

whenever required; hence, they have to go to private facilities, or facilities nearby. Often they resort to buying medicines from pharmacies or visiting informal providers.

There are differing views of government representatives and persons with disabilities when it comes to accessible infrastructure. According to government representatives who were KIIs, many health care facilities should have by now, and future facilities will install disability friendly infrastructure and facilities, according to the policy and new plan of action. However, according to persons with disabilities and stakeholders' accounts, these facilities are especially absent in majority of primary, secondary level care facilities, and the private facilities do not follow the policy. Few government representatives in the KIIs revealed that most of the health care facilities in Bangladesh were built long before the Disability Act and they did not have provisions for persons with disabilities in the facility design. They cannot be all reconstructed, and even if the New Plan of Action/Policy imposes provision of disability friendly infrastructure, it will be difficult and resource-exhaustive to include these provisions into those facilities; in some cases, it will be impossible without reconstruction. In the tertiary level facilities, new wings or buildings are being added to include such provisions where budget is available, but for the older infrastructures further modifications are not being possible.

"Other than very old buildings, all government health facilities have accessible infrastructure including ramps."- Government representative, KII

"*There are no ramps or lifts in the facilities....even if there are ramps in few facilities, they are not built according to guidelines. If you try to go up on a wheelchair, you will fall. We have had cases...."*- DPO representative, Stakeholder Workshop

Accessibility of PWDs to health services being limited by inappropriate infrastructure in health care facilities and public transportation facilities are also reported by Diwakar (2017), World Bank and PROB (2015), BLAST (2015) and by Ali (2014). It is also reported that in Bangladesh, formal health care utilization among persons with disabilities was reported to be quite low, and in rural areas in 81% cases consultation was sought from the informal sector (Razzaque, Nahar, Akter, Khanam, & Streatfield, 2010; Hosain& Chatterjee, 1998).

Absence of provisions in public transportation and Affordability

The research found that, although according to the National Disability Act, the public transportations (buses, trains) are required to have reserved seats for persons with disabilities, in reality there are no seats reserved; nor do they have any space allocated for wheelchairs. Usually these seats are filled up by passengers because they pay for the seats. There is no provision of ramps for wheelchairs to get into the buses and trains either.

The buses do not stop at the allocated sites rather they haul passengers coming in randomly from the roads, and there is always a crowd surrounding the doors with the helper pushing people inside. This makes it nearly impossible for persons with disabilities to even enter the bus and navigate a seat on the bus. Most persons with disabilities shared that they require more time and space to get into the bus. Many respondents reported that the buses do not stop for enough time, rather they rush within minutes, and the conductors/helpers are often very rude and reluctant to take persons with disabilities into the bus; even, showing an identity card does not improve the situation.

One respondent said:

"It's difficult for me to use public transport as conductors and helpers are reluctant to take me. Even if they stop for me other passengers refuse to let me in" -Male, 40 years old, on a wheelchair due to paralysis from waist down, from urban Savar.

The lack of provisions in public transports meant higher costs incurred by persons with disabilities while seeking care, as they need to avail private transports (hired car, CNG, taxi, van etc.) in most cases, which have higher fares. This extra cost only adds to the inability to afford health care and de-motivates their health care seeking until emergency.

Differing views on the reasons for such inaccessibility in public transportations was expressed by government representatives and, the persons with disabilities and the stakeholders. While the government representatives implied that the problem lay with the lack of awareness of persons with disabilities themselves about their rights and a general lack of awareness of the public of the rights of persons with disabilities. Whereas, the diverse NGO, INGO and DPO stakeholders stated that there was a general lack of policy implementation and law enforcement was a major underlying challenge.

The accessibility of persons with disabilities to health services is a huge problem and this lack of facilities in public transportations is also reported by research studies in Bangladesh, such as by Diwakar (2017), World Bank and PROB (2015), BLAST (2015) and by Ali (2014).

To add to this challenge, affordability is a huge issue for persons with disabilities, who incur high treatment cost for chronic conditions and complications. The cost of paying for private transportation also adds to the overall cost of treatment. According to policy documents, Government is supposed to provide free treatment to the poor persons with disabilities, and this was corroborated by government representatives in KIIs, stakeholders and persons with disabilities interviewed, the reality was that a majority of these patients do not get free service. There are 'one stop service centers' for persons with disabilities in the tertiary level government hospitals, and if treatment is accessed through them or an application for free services made to hospital head, then the services are free of cost. Many do not go through this procedure because they didn't know of this service, lack of information at the facility and delays in accessing and starting treatment. For others, many of the medicines (which are made free of cost for all by government), physiotherapy and simple procedures in outdoors are free, but for most of the medicines, especially those which are not made free by government, those need to be bought. Complex procedures and treatments are even costlier. Even in the government facilities, out of pocket payment occur, due to discrepancies and weak governance and laxck of monitoring and accountability.

"I was moving from room to room on my crutch, somewhere I was buying the ticket, then I was buying bandages and medicines, one ward boy said he can arrange a wheelchair for me if I pay him 300-400 taka, so I did. The doctor did not take any fees, but I had to pay some money for the medicines, they were not full free."- Male, 48 years, one leg amputated, from urban Savar

Moreover, the facility of 'one stop service' is not available in primary and secondary level, as well as in private facilities, which are the usual points of first contact for illnesses. Also, the tertiary facilities are usually quite distant from residences, and that results in high

transportation costs. The treatment cost, distance and transportation costs often lead to high uptake of services from informal sectors rather than formal care.

"I do not go to private clinics because it is not accessible on wheelchair, and it costs a lot. I like government *hospitals because they tend to you right away and you get facilities to move in a wheelchair. However, the* government *hospital is quite far from my home and travelling by bus for long time makes my condition worse. So I only seek care when I absolutely have to. Otherwise, I get my medicines from the pharmacy here…"* -Male, 52 years old, paralyzed from waist down, from peri urban Savar

Assistive devices such as tri-cycle, wheelchairs, artificial limbs, etc. are found to be expensive from accounts of persons with disabilities. Although CRP gives them to registered persons with disabilities for cheaper price and JPUF (government) gives them for free, many persons with disabilities do not know about it. Majority of the respondents in the study reported of buying the wheelchairs themselves costing them around 20,000-21,000 taka (approximately US$256) for a good quality device, a huge cost for the family and individual.

Photo: Middle aged man, born without lower limbs, has been using a short stick as a support for mobility in his daily life

"I have not heard about government *giving wheelchairs, I did not get it from them either. I applied for an identification card months back and I still haven't gotten it. How long do I wait for the wheelchair who knows? I bought it with 21,000 taka* (approximately US$256)*. Now I wonder, I saved up the money from my shop business for many months and bought it. How many of us are able to do that?"* -Male, 50 years old, paralyzed from waist down, from peri urban Savar

An analysis of the World Health Survey (2004) data for 15 developing countries suggests that households with disabled members spend relatively more on health care than households without disabled members and persons with disabilities demonstrate a strong need for better access to health care services (55.3%), medications (21.3%), technical devices (17.5%), and financial help for basic needs (52.5%). In Bangladesh, formal health care utilization among persons with disabilities was reported to be quite low, and in rural areas in 81% cases, consultation was sought from informal sector (Razzaque, Nahar, Akter, Khanam, & Streatfield, 2010; Hosain & Chatterjee, 1998). Existing barriers to access transportation, especially public transportation, further complicates accessibility to health care for persons with disabilities (BLAST, 2015; World Bank and PROB, 2015). In a survey done by BLAST (2015), 52 % of the respondents said

that Government hospitals do not provide medicine or treatments for free for persons with disabilities who are poor, although the Ministry has issued rules in accordance with the Rights and Protection of Persons with Disabilities Act 2013, stating that this should be the case.

Lack of skilled and sensitive health care providers (HCPs)

The IDIs and FGDs with persons with disabilities and with KIIs with the stakeholders found a common concern that HCPs who are not specialized lack the skills to detect early and treat disabilities and complications. HCPs cannot examine nor use appropriate equipment and techniques to examine persons with disabilities, and they lack knowledge about treatment of disability, related co-morbidities and its complications. Especially, HCPs lack skills in dealing with female PWDs during pregnancy, ANC-PNC, child birth and related complications. Often this leads to a chain of unnecessary and expensive referrals and delays in timely, appropriate diagnosis and treatment. One respondent in IDI said:

'My reports said I had UTI, and the doctor seeing the report immediately started to scold me. He said I had to be more careful, as I already had a condition making it difficult to deal with me….I felt very bad listening to him, but the truth is being paralyzed from chest downwards has its consequences, I am bound to be more prone to develop UTI' - Female from urban Dhaka, middle-aged; participant in stakeholder workshop

The respondents in IDIs, FGDs reported that there was an in general attitude among health care providers that, as the person is disabled, he or she must be poor and will not be able to bear the cost of treatment. It was very apparent in the provider's behavior, and oftentimes, the respondents were directly asked about whether they can afford the treatment or not. Some of the respondents mentioned they understood that the doctor and nurses were looking down at them. This negative attitude often leads to they believe delayed and inadequate treatment.

The study also found that health care providers lacked sensitivity while dealing with patients with physical disability. Many respondents reported the providers had a stigma against them and often tried to make it sound like the disease was their fault, as they should have prevented it somehow. One respondent mentioned of her experience:

"The doctor told me I was having miscarriages because of my disability (paralyzed from waist down) even before any test was done, and later on it was revealed that it was because of high blood sugar not because of the disability after the test results came in. He had said, why are you trying to become pregnant when you are disabled? He told me not to cry over them, he said the miscarriages were a blessing in disguise, and I would have understood this hard truth in future". - Female, 35 years old, paralyzed from waist down, from peri urban Savar

This lack of sensitivity seems to be resulting from either lack of skills on how to treat a person with disability or lack of knowledge regarding the condition, or simply the stigma, or out of irritation as the persons with disabilities need more time and assistance during treatment. Poverty itself also makes persons with disabilities more vulnerable to social discriminations. They are stigmatized more and they are frequently victims of health care providers' negative attitude when they go to seek care.

The NGO stakeholders who work with females with physical disability reported that when these women go to the providers for check-up or health care during pregnancy and delivery, they are quite often met with rude behavior and remarks:

''Why did you get pregnant?' The nurse had said to the girl (a beneficiary of the NGO who does not have one leg). 'Don't you understand you are disabled? You are only creating more problems for everyone''- NGO representative, Stakeholder Workshop

Islam, Mondal, & Kabir (2018), Razzaque et al. (2010), and Hosain & Chatterjee (1998) reported that health services were grossly underutilized by persons with disabilities compared to general population in Bangladesh. These studies, along with BLAST (2015) and World Bank and PROB (2015), implicate lack of appropriate skills, responsiveness, knowledge and early detection abilities of providers to be a major reason for the underutilization. Reports by BLAST (2015) and World Bank and PROB (2015) express that health care providers generally lack knowledge on how to provide services to women with disabilities when they become pregnant, including pre natal, natal and post-natal care. In a survey by BLAST it was also reported that, women with disabilities were particularly vulnerable to discrimination, neglect, violence and injustice (BLAST, 2015). Rahaman, Habib & Chakladar (2017) and World Bank and PROB (2015) implicates lack of respect by health care providers towards persons with disabilities as a major cause of underutilization of services in our country. Lack of quality of care, appropriateness of services, knowledge and responsiveness of providers are reported to result in underutilization of services (Lawthers, Pransky, & Himmelstein, 2003).

C. Macro-level Challenges and Policy gaps

The following challenges were identified by NGO stakeholders and government representatives (KIIs).

Centralization of power at Ministry of Social Welfare

The research found that all issues regarding disability, including health care services are dealt by the Ministry of Social Welfare. Representatives from stakeholder NGOs saw this as a hindrance in the mainstreaming of disability issues, as the government themselves is treating persons with disabilities as socially marginalized. It was also reported that having one ministry responsible for the policies and policy implementation of disability issues leads to a centralization of power, negating roles of other actors, for example- the role of Health Ministry in creating policies and providing services to persons with disabilities and there is overall less accountability. There is a resentment among Health Ministry as they did not take part in generation of policies despite being the best suited to cater for health service provision; their expertise was not considered. This often results in discontentment between different relevant Ministries and NGOs; also, it leads to a lack of coordination of actions and policies followed by different Ministries.

Policies are there, but there is no proper implementation

The respondents reported that although the policies and laws that exist in Bangladesh are quite adequate in protecting the rights of persons with disabilities, but they need to be implemented. The main problem is that there is no enforcement and implementation of these policies. There is an overall lack of monitoring by the Ministries as well as the law enforcement agencies to ensure that the policies and laws are followed.

Lack of coordination between actions of different ministries

The interviews with Stakeholders found that to implement a policy laid down by Ministry of Social Welfare, it is mandatory that Ministry of Health as well as other Ministries (for example- Civil Engineering) coordinate and act accordingly to ensure health services. Unfortunately, the Ministries themselves lack coordination between them for various reasons. One of the reasons identified was not ensuring participation or taking into account the capacities of different Ministries while laying down policies. Other reasons were high staff turnover due to transfers in different positions, which impacts on continuity and commitment as well as follow up and ensuring implementation of policies and decisions.

Lengthy bureaucratic processes hindering implementation of policies and decisions

A major problem in implementing actions and decisions was bureaucratic delays and some shared that it takes a very long time for files to move around in Ministries and for a decision to be taken. This time lag is even longer while it trickles down from Ministry to Capital to regional then local office finally reaching the point of action. This was the norm in the government system, as there is no decentralization and autonomy in decision-taking by the implementing wings under Ministry, so the simplest decisions, even if it is buying a wheelchair, needs to be approved and authorized by the Ministry.

Challenges in acquiring trained human resources in health facilities

The government representatives mentioned that the process of hiring through entry exams and positioning of trained human resources in health facilities, especially at tertiary level, such as doctors, nurses, ward boys and other hospital staff, is very lengthy and time consuming. This process can take up to a few years before new recruitment happens. There is also an unequal distribution of staff, doctors and nurses across facilities which do not meet the requirements of individual facilities. This results in vacant positions and shortage of staff, including trained doctors. The key informants implicated the lack of autonomy of implementing organizations and facilities in hiring staff and a top-down approach of the government to be underlying reasons for this.

Placement and training of staff in positions of power, who do not have the expertise nor political will

A practice within Ministries is to favor politically affiliated personnel in responsible positions of action, and not personnel who actually have expertise on disability issues. This leads to a lack of sensitivity, interest as well as expertise when it comes to decisions, implementation and monitoring of service provision for persons with disabilities. Also, it leads to disdain among staff with actual expertise resulting in high staff turn-over.

Lack of adequate budget and discrepancies in spending available funds

There is a lack of budget allocation in disability issues. Since the political will had been heightened, there has been a flow of more funds and more initiatives are being taken, however, they are still not adequate to establish disability as a mainstream issue nor to provide better services for the disabled population in general. Another problem regarding disbursement and use of funds is the lack of accountability. It was reported that while government funds are not much, but audits regarding spending is strict; INGOs invest a lot of soft funds in disability issues and provide technical support to the government. However, the INGOs demand follow-ups and want government to use the money to gain some form of sustainability in the long run. Unfortunately, since there is no audit from government regarding expenditure of these INGO funds, the activities and expenditure often do not match the intended outcome. When the donors do not get adequate results or reporting, they stop or withdraw funds.

Discrepancies in identification of PWDs and disbursing Identification Cards

Although Ministry of Social Welfare is conducting the ongoing survey to identify persons with disabilities and providing them with Cards enabling them to exercise rights, such as free treatment, seat in transports, rations, etc., the system through which it is done is very vague. Doctors in local health care facilities nationwide, especially primary and secondary level facilities are responsible for identification and notification of persons with disabilities to Ministry database. However, not all of these doctors (apart from tertiary, who are specialized) are trained to clinically identify persons with disabilities, so there is a chance of under and over estimation of the type and number of persons with disabilities. Another system barrier is encountered when doctors are not closely monitoring and identifying all the cases of disability that they are encountering. As per the norm, medical health practitioners are supposed to identify and report the disability cases and then guide that individual to the proper authorities for acquiring identity cards and ration cards. However, the persons with disabilities interviewed during the IDIs and FGDs reported that they did not get any information regarding cards from their healthcare providers. In the absence of any guidance after identification, they often had to rely on hearsay from neighbors, friends or community members for getting information about their rights.

There is also an allocated ration card for the PWDs, through which they are entitled to get money, about 700 taka per month. Many of the respondents reported that although the Cards were meant to be given free by local authority, it was not the case for many and they had to pay the local influentials/chairman/local MP etc. to get the Cards. Although the allocated money was to be disbursed every month, the respondents who had the card reported that they get it every three or four months as a lump sum, that too at the rate of about 600/month instead of the allocated 700.

This lack of transparency and weak governance and absence of monitoring leads to incorrect registration as well as actual PWDs not getting the card and related benefits, while many who are not PWDs may get the benefits.

'Collecting card is very complex. Places to go are not accessible. We have to pay to local members or chairman to get disability card. Varying from 2000 to 4000 taka. As I was not able to pay I couldn't get card. I don't get money.'- Male, 48 years old, in FGD

Weak governance

The study respondents reported that the system through which service provision will be ensured currently lacks governance and accountability; it requires monitoring and supervision by a governing body reaching through all levels. Otherwise, different bodies are working at different times with no coordination between them, diluting efforts. There is no concerted effort or focused decisions on which the different agencies are working; there is no clear plan or vision, and everyone is involved in piecemeal work. Without good governance under which all agencies can work together in collaboration, the efforts made are not going to be effective. Corruption at all levels and lack of communication between agencies, between and within Ministries, Ministries and NGOs need to be curbed. A system of accountability needs to be established so all actors are responsible for using the limited resources to effect actual change.

Recommendations

The study would like to make the following recommendations, based on discussions with the different respondent groups:

1. Ending the vicious cycle of poverty through opportunities for education and employment. This was recommended by stakeholders in Workshop and persons with disabilities.

2. Raising awareness to remove stigma and promote of rights of persons with disabilities, starting from the grass root level. At present, the government holds meetings with the local representatives and community leaders at the Upazilla level and community level and relies on them for information dissemination. The study recommends using media and BCC as important tools for mass communication, and to make relevant provisions and information dissemination within health care facilities (the point of contact for care) regarding facilities, benefits and cards for persons with disabilities.

3. Training and sensitization of HCPs for appropriate health care provision and removal of stigma was emphasized by persons with disabilities and Stakeholders.

4. Expanding provision of wheelchairs, artificial limbs, crutches etc. to all persons with disabilities, and implementation of policies to ensure disability-friendly infrastructure and public transportation, was recommended by all respondents.

5. Law enforcement to preserve rights of persons with disabilities, and strong monitoring & supervision across all levels in the health system, was recommended by stakeholders.

6. Good governance and accountability in a decentralized health service system, coordinated interventions and policies, and appropriate use of resources without corruption, was strongly recommended by government representatives, and also stakeholders.

Conclusion

Disability not only has physical consequences, but also psychological and emotional impacts, as well as economic and socio-cultural consequences, affecting self-perception of PWDs which affects their sense of self as well as their health care seeking behavior. While not all of them suffered from internalized stigma, many shared that stigma was widespread in the community and within the family. It is critical to also have more in-depth comprehensive research on the impact disability has on individuals' every lives, emotional and mental well-being and physical health.

The challenges existing at policy and macro-level play significant role in negatively impacting on the implementation of interventions and policies that facilitate service uptake by persons with disabilities, and therefore, need to be addressed. This was a short exploratory study into the macro-level challenges, and it is necessary to have larger studies encompassing different levels of health system to understand the challenges better and generate more specific recommendations.

Information dissemination at appropriate places, such as health facilities, doctor's chambers etc. and awareness raising across communities, including persons with disabilities is critical for advocating the basic human rights of persons with disabilities and to mainstream their needs. Appropriate strategies to do so is highly recommended.

To conclude, this study was a quick snapshot of the health needs and barriers to health care. The aim is for BRAC JPGSPH to undertake a nation-wide study on Disability looking into the situation, needs and current state of sexual and reproductive health and rights of persons with disabilities, towards the second half of the year.

Limitations

The study was conducted within a limited scope with limited sample size. The persons with disabilities interviewed in the study belonged to a privileged group already, who had access to CRP and VASD. Hence, their accounts will not be representative of all persons with disabilities of Bangladesh in general; and there are many more issues and views out there that we could not explore within the limited scope of our study.

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