

'We can also make change'

Piloting participatory research with persons with disabilities and older people in Bangladesh

April 2015



By the 'Voices of the Marginalised' consortium
(Sightsavers, HelpAge International, ADD
International, and Alzheimer's Disease International)

Authors: Danny Burns and Katy Oswald
Institute of Development Studies (IDS)

November 2014

Lead authors: Danny Burns and Katy Oswald

Mohammad Akkas Molla
Selina Begum
Md Kamal Hossain
Abdul Matin
A H M Kamruzzaman
Salamot Ullah
Hafez Mohammad Jafar Alam
Rozina Akter
Nazma Akter Rasheda
Mohammad Fazlul Haque
Shefali Bala Dey
Lipi Rahman
Most Samira Khatun
Md Al Amin
Nasima Khatun
Md Elias Talukder
A S M Ashiqur Rahman
Md Fazlul Karim

Known as 'we can also make change' team

Acknowledgement

This document is an output from the Voices of the Marginalised, a consortium formed of Sightsavers, HelpAge International, ADD International, and Alzheimer's Disease International, with funding from Sightsavers. Many individuals are to thank for the success of this pilot study: the 18 peers researchers in Bangladesh who collected and analysed the studies, the persons with disabilities and older people who accepted to share their stories; the staff from Sightsavers, HelpAge International, ADD International and Danny Burns and Katy Oswald from IDS for leading the research. Thank you also to Naomi Marks for editing the report. The views expressed are those of the peers researchers and do not necessarily represent those of the Consortium.

**For more information, please
contact Sightsavers policy team:
policy@sightsavers.org
or consult Sightsavers website:
www.sightsavers.org/voices**

Burns, D., Oswald, K. and the 'we can also make a change' team (2015)

Cover image: ©Peter Caton/Sightsavers

Please note: the images used in this report do not show the participants or interviewees in the Voices of the Marginalised project. We wish to protect their identities.

Contents

| | |
|---|-----------|
| 1. Executive summary | 8 |
| 1.1 Introduction | 8 |
| 1.2 Methodology | 8 |
| 1.3 Findings | 9 |
| 1.4 Conclusion | 9 |
| | |
| 2. About this research | 11 |
| 2.1 The community peer researchers from Bhashantek | 11 |
| 2.2 The community peer researchers from Cox's Bazar | 11 |
| 2.3 The peer researchers from Bangladesh NGOs | 12 |
| 2.4 Supporting facilitators | 13 |
| 2.5 Research facilitators | 13 |
| 2.6 A note on terminology | 13 |
| | |
| 3. Introduction | 14 |
| 3.1 Persons with disabilities in Bangladesh | 15 |
| 3.2 Older people in Bangladesh | 15 |
| | |
| 4. Research design and methodology | 17 |
| 4.1 Our definition of disability | 17 |
| 4.2 What is participatory research? | 17 |
| 4.3 What is peer research? | 17 |
| 4.4 Collecting stories | 18 |
| 4.5 Site selection | 18 |
| 4.6 Selection of peer researchers | 18 |
| 4.7 Ethics | 19 |
| 4.8 A note on representation and generalisation | 19 |

| | | |
|-------------|---|-----------|
| 4.9 | Research design and planning workshop: November 2012 | 19 |
| 4.10 | Mid-term workshop: January 2013 | 20 |
| 4.11 | Research analysis workshop: April 2013 | 21 |
| 4.11.1 | Community peer researchers | 21 |
| 4.11.2 | NGO peer researchers | 22 |
| 4.12 | Verification workshop: June 2013 | 22 |
| 5. | Analysis and discussion | 25 |
| 5.1 | Accidents and disasters | 25 |
| 5.1.1 | Accidents or natural disasters causing disability | 25 |
| 5.1.2 | Disability and older age contributing to higher risk of accidents | 25 |
| 5.1.3 | What should be done? | 26 |
| 5.2 | Access to education | 26 |
| 5.2.1 | Lack of money and stipends | 26 |
| 5.2.2 | Lack of infrastructure and facilities | 26 |
| 5.2.3 | Disability discrimination and bullying | 27 |
| 5.2.4 | Gender discrimination | 28 |
| 5.2.5 | Unsupportive family | 28 |
| 5.2.6 | What should be done? | 28 |
| 5.3 | Livelihoods | 29 |
| 5.3.1 | Difficulty finding a job due to disability | 29 |
| 5.3.2 | Begging as a livelihood choice | 31 |
| 5.3.3 | Access to affordable credit | 31 |
| 5.3.4 | Pensions and disability allowance | 32 |
| 5.3.5 | What should be done? | 33 |
| 5.4 | Medical treatment | 34 |
| 5.4.1 | The cost of treatment | 34 |
| 5.4.2 | Corruption and discrimination | 35 |
| 5.4.3 | Medical knowledge | 35 |
| 5.4.4 | Alternative medicine | 36 |
| 5.4.5 | What should be done? | 36 |
| 5.5 | Family support | 37 |
| 5.5.1 | Older people lacking family support | 37 |
| 5.5.2 | Persons with disabilities lacking support | 39 |
| 5.5.3 | What should be done? | 39 |

| | | |
|-------------|---|-----------|
| 5.6 | Exclusion and mistreatment | 39 |
| 5.6.1 | Exclusion and mistreatment of persons with disabilities by family members | 39 |
| 5.6.2 | Exclusion and mistreatment of persons with disabilities by the community | 40 |
| 5.6.3 | Exploitation of persons with disabilities | 41 |
| 5.6.4 | Exclusion and exploitation of older people | 42 |
| 5.6.5 | What should be done? | 43 |
| 5.7 | Superstition | 43 |
| 5.7.1 | Bad spirits | 43 |
| 5.7.2 | 'Sin' and 'bad behaviour' | 44 |
| 5.7.3 | Other myths | 44 |
| 5.7.4 | What should be done? | 45 |
| 5.8 | Access to services | 45 |
| 5.8.1 | Specific services for older people | 45 |
| 5.8.2 | Health services | 46 |
| 5.8.3 | Lack of services for people with mental illnesses | 46 |
| 5.8.4 | Insufficient services for people with intellectual impairments | 46 |
| 5.8.5 | Infrastructure | 46 |
| 5.8.6 | What should be done? | 47 |
| 5.9 | Mobility | 47 |
| 5.9.1 | Mobility and physical disabilities | 47 |
| 5.9.2 | Mobility and people who are blind or have low vision | 47 |
| 5.9.3 | Mobility and people with hearing and speech impairments | 48 |
| 5.9.4 | What should be done? | 48 |
| 5.10 | Marriage | 48 |
| 5.10.1 | Marriage and women with disabilities | 48 |
| 5.10.2 | Mistreatment of women with disabilities | 49 |
| 5.10.3 | What should be done? | 50 |
| 5.11 | Land | 50 |
| 5.11.1 | Slum living | 50 |
| 5.11.2 | Land inheritance | 51 |
| 5.11.3 | What should be done? | 51 |
| 5.12 | Rape and sexual abuse | 52 |
| 5.12.1 | Women, disability and vulnerability | 52 |
| 5.12.2 | Particular vulnerabilities | 52 |
| 5.12.3 | Power, rape and sexual abuse | 53 |
| 5.12.4 | Views of the community peer researchers | 54 |
| 5.12.5 | What should be done? | 55 |

| | | |
|-------------|---|-----------|
| 5.13 | The role of grassroots community-based organisations | 56 |
| 5.13.1 | Supporting the wrong kinds of activities | 56 |
| 5.13.2 | Lack of accountability | 56 |
| 5.13.3 | Do NGOs adopt the right approach? | 56 |
| 5.13.4 | Community involvement and sustainability | 57 |
| 5.13.5 | The priorities of NGOs | 58 |
| 5.13.6 | Capacity development and service delivery | 60 |
| 5.13.7 | Views of the community peer researchers | 60 |
| 6. | Evaluation of the peer research process | 63 |
| 7. | Conclusion | 67 |
| 7.1 | Key areas | 67 |
| 7.2 | Challenges | 68 |
| 7.3 | Empowerment through research | 68 |
| | Annex 1: The guidelines for community and NGO peer researchers | 69 |

1. Executive summary

1.1 Introduction

Sightsavers, HelpAge International, ADD International, and Alzheimer's Disease International worked together with the Institute of Development Studies (IDS) to bring the perspectives of those who live in poverty or who are highly marginalised into post-2015 policy making. This report, entitled "We can also make a change", presents the findings of the Voices of the Marginalised pilot research project. It draws on the real-life stories of persons with disabilities and older people, as told to researchers by persons with disabilities, family members of persons with disabilities and older people themselves. The research was carried out in Bangladesh, the world's seventh most populous country and one experiencing rapid demographic change.

The aim of the research was to understand better the experiences of social, political, and economic exclusion of persons with disabilities and older people from their own perspectives. Although the facts of exclusion are widely documented, the reality of it has been less explored. This is important though, both to further understand poverty and exclusion and to determine whether the rights of persons with disabilities and older people are – or are not – being upheld.



©Shafiqul Alam Kiron/Sightsavers

1.2 Methodology

The project made use of a form of participatory research known as peer research. Participatory research is intended to break down the divide between researchers and participants. It is research WITH people, not ON people. In peer research, the researchers are people rooted within particular constituencies or communities.

Two groups of peer researchers were supported to undertake the project:

1. Community peer researchers: Poor and/or excluded persons with disabilities and older people from each of the two selected research sites: Bhashantek, an urban slum in Dhaka; and Cox's Bazar, a rural area in southeast Bangladesh.
2. Non-Governmental Organisations (NGO) peer researchers: Staff from local Bangladeshi NGOs who work with persons with disabilities and older people.

Eighteen peer researchers were selected in total with the task to gather stories. They were supported in this process through a series of workshops facilitated by researchers from IDS. These were held from November 2012 to April 2013. The draft research report was verified by the peer researchers at a workshop in June 2013.

1.3 Findings

From the stories collected and analysed, the peer researchers identified 13 priority areas that affect persons with disabilities and older people. These were:

- accidents and risks
- access to education
- livelihoods
- medical treatment
- family support
- exclusion and mistreatment
- superstition
- access to services
- mobility
- marriage
- land
- rape and sexual abuse
- the role of grassroots community-based organisations

There was significant overlap in the issues identified by the two groups of peer researchers. However, only the NGO peer researchers identified rape and sexual harassment. This discrepancy prompted a workshop discussion. The community peer researchers agreed that girls and women with disabilities are vulnerable to rape and sexual harassment, but they explained that the shame associated with sexual abuse meant it was not spoken about openly.

A second issue that failed to be identified by the community peer researchers was the role of grassroots organisations. In a workshop discussion around this, the community peer researchers expressed a number of negative views around NGO activities.

1.4 Conclusion

The stories gathered in the Voices of the Marginalised project tell of the experiences of persons with disabilities and older people in one country, at one time, providing valuable testament to the considerable equality and poverty challenges they face. Through the stories gathered, the issues that are most critical to persons with disabilities and older people are made clear. The detail of their testimonies reveals how and why discriminatory dynamics are generated and sustained, and how they impact on people.

Thirteen separate but intersecting issues were identified by the peer researchers as critical to “people like them, with significant overlaps between them. Chief among them was the critical issue of insecure livelihoods. Persons with disabilities and older people have little access to income. Yet the stories gathered illustrate how transformative an income can be in terms of independence, status and self-esteem. Poor access to services, chiefly as a result of poor infrastructure, can also be seen as key, as too the everyday discrimination and exclusion faced by persons with disabilities and older people. Rape and sexual harassment add extreme hardship to the lives of girls and women with disabilities who already face gender discrimination, poverty and exclusion. Finally, the people living in Bhashantek slum in particular singled out land – and the difficulty of access to it, as an issue.

The peer researchers demonstrably enjoyed participating in the research project, learned new skills, and felt confident to speak about both disability and ageing issues. Importantly, the research modelled the process of empowerment itself. From the moment this group of persons with disabilities and older people came back from gathering stories and exclaimed, “We are researchers now”, the potential for real transformation was realised.



2. About this research

Sightsavers, HelpAge International, ADD International and Alzheimer's Disease International worked together with the Institute of Development Studies (IDS) to bring the perspectives of those who live in poverty or who are highly marginalised into post-2015 policy making. This report, entitled "We can also make change", presents the findings of the Voices of the Marginalised pilot research project.

It draws on the real-life stories of persons with disabilities and older people in Bangladesh, as told to researchers by persons with disabilities, family members of persons with disabilities and older people themselves.

The research was undertaken by a group of peer researchers from Bhashantek, Dhaka, and villages in the Cox's Bazar district of Bangladesh, all of whom were persons with disabilities, older people or people with an immediate member of their family with a disability, together with a group of peer researchers from Bangladesh NGOs who work with persons with disabilities and older people.

2.1 The community peer researchers from Bhashantek, Dhaka

“ My name is Mohammad Akkas Molla. I am 45 years old and I live in Bhashantek in Dhaka. I am a hawker, selling medicine on the street. I am married and have two children, one son and one daughter. I am visually impaired. I am proud that I am contributing to the welfare of disabled and older people by participating in this initiative.”

“My name is Selina Begum. I am 44 years old and I live in Bhashantek in Dhaka. I am a hawker and sell clothes on the street. I am married but I was abandoned by my husband. I have one son, a daughter-in-law and one grandson. I am disabled. I am proud that I lead a self-help group for people with disabilities and that I can help them.”

“My name is Md Kamal Hossain. I am 35 years old and I live in Bhashantek in Dhaka. I sell clothes. I am married and I have two sons. My right hand and right leg were broken, so I am now disabled. I am very proud of being

involved with this research. This is the first time I've been involved in anything like this.”

“My name is Abdul Matin. I am 72 years old and I live in Bhashantek in Dhaka. I once had my own business, but since I've had eye problems I haven't been able to work. I am married and I have three sons and one daughter. I had a cataract operation and lost the vision completely in one eye and partially in the other. So I am both old and disabled.”

“My name is A H M Kamruzzaman. I am 45 years old and I live in Bhashantek in Dhaka. I have my own confectionery and tea stall. I am married and have two sons. I am disabled because my right hand and leg are broken. I am proud that I am not dependent on anybody and have my own business and a regular income, despite my disability.”

2.2 The community peer researchers from Cox's Bazar

“My name is Salamot Ullah. I am 21 years old and I live in Jhilonja in Cox's Bazar. I'm a student, studying at higher secondary school. I am unmarried and have three brothers and four sisters. I am disabled. One of my legs is shorter than the other. I'm proud that I am part of a self-help group that works with disabled people.”

“My name is Hafez Mohammad Jafar Alam. I am 35 years old and I live in Jhilonja in Cox's Bazar. I am an assistant officer-in-charge for a life insurance company. I am married and I have three sons and two daughters. I have a visual disability. I am proud that I have been involved with disability organisations since

I was eight years old and I want to continue being involved for the rest of my life.”

“My name is Rozina Akter. I am 25 years old. I live in Jhilonja in Cox’s Bazar. I’m studying for an MBA (accounting) in Cox’s Bazar government college. I am unmarried and have six sisters and three brothers. I was affected by rheumatic fever at the age of six and as I had no proper treatment I became disabled. I participated in the research to do something for disabled people, particularly women with disabilities.”

“My name is Nazma Akter Rasheda. I am 18 years old and I live in Jhilonja in Cox’s Bazar. I am a student and a member of a person with disabilities (PWD) self-help group. I am unmarried and have three sisters and six brothers. I am disabled. I have a club foot on my left leg. I am proud to be part of this research. As a disabled person, I tried to bring out the sufferings of disabled people and older people in my community.”

“My name is Mohammad Fazlul Haque. I am 72 years old and I live in Jhilonja Sadar in Cox’s Bazar. I sell electronic goods. I am married and I have three sons and one daughter, all of whom are married. I am proud of my sons and daughters.”

“My name is Shefali Bala Dey. I am 42 years old. I live in Jhilonja in Cox’s Bazar. I am a housewife. I have one daughter who has a visual disability. She’s a member of a PWD self-help group. I am married and have three daughters and two sons. I do welfare work in my community and I am proud of that.”



2.3 The peer researchers from Bangladesh NGOs

“My name is Lipi Rahman. I am 39 years old and I live in Dhaka in Bangladesh. I am a programme officer at the Resource Integration Center (RIC), an NGO that works with older people. I am unmarried and I’m proud to be an independent woman.”

“My name is Most Samira Khatun. I’m 23 years old and I live in Godagari, Rajshahi, Bangladesh. I’m a graduate student in political science and I’m Treasurer of Zila Badhon Protibondhi Sangstha, a PWD organisation. I have a visual disability as I only have sight in one eye. I am unmarried and am proud that I am brave and face many challenges in order to progress in my life.”

“My name is Md Al Amin. I am 25 years old and I live in Dhaka, Bangladesh. I am a community mobiliser for ADD. I am unmarried and have three brothers and two sisters. I am disabled as a result of polio. I am proud that I graduated with honours successfully, despite my disability.”

“My name is Nasima Khatun. I am 42 years old and I live in Palash, Narsingdi, Bangladesh. I am a community organiser for the Bangladesh Women’s Health Coalition (BWHC), an NGO that works with older women. I am married and have two daughters and one grandson. I also have two brothers and four sisters, and one of my sisters is disabled. I have been doing my job for a long time and I have become independent. I have managed to make my own home, which makes me proud. I work for the welfare of older women and that also makes me proud.”

“My name is Md Elias Talukder. I’m 32 years old and I live in Barisal, Bangladesh. I am a project supervisor at the Centre for Services and Information on Disability (CSID). I am unmarried and have three brothers and one sister. I am proud of my mother. She’s a great mother.”

“My name is A S M Ashiqur Rahman (Amit). I am 30 years old and I live in Dhaka, Bangladesh. I am the Treasurer of the Bangladesh Visually Impaired People’s Society (BVIPS). I am married and I have one brother and three sisters. I have a visual disability. I’m proud of my work, which deals with IT software for visually impaired people.”

“My name is Md Fazlul Karim. I am 35 years old and I live in Dhaka, Bangladesh. I am a programme organiser for BVIPS. I am married and I have one son. I am proud of the work I do for people with disabilities.”



2.4 Supporting facilitators

Nusrat Zerín

Programme Officer, Sightsavers Bangladesh

Jahangir Alam

Programme Officer, Sightsavers Bangladesh

Shashwatee Biplop

Senior Advisor, Social Protection and Policy, HelpAge Bangladesh

Fazlul Haque

Capacity Development Facilitator, ADD Bangladesh

2.5 Research facilitators

Danny Burns

Research Fellow, IDS, UK

Katy Oswald

Research Officer, IDS, UK

2.6 A note on terminology

Throughout this report the term “persons with disabilities” is used as this is an internationally accepted term. When participants are quoted, however, “people with disabilities” and other terms may be used as this more accurately reflects people’s everyday language.

3. Introduction

Global ageing has a major influence on disability trends. There is higher risk of disability at older ages and the population of Bangladesh is ageing at an unprecedented rate. By 2030, 16.6 per cent of the world's population will be aged 60 and over, and of those 73 per cent will live in the developing world.¹

Globally, persons with disabilities face wide-spread social, economic, and political exclusion.

Age-related health problems that can affect sight, hearing, mobility, and mental functioning mean that older people are particularly vulnerable to the poverty-related effects of disability. Older people may not consider

themselves as having a disability despite enduring significant difficulties because they consider their level of functioning appropriate for their age. Therefore this research worked with persons with disabilities, as well as older people who may not self-identify as having a disability.

Globally, persons with disabilities face widespread social, economic, and political exclusion. They are routinely excluded from participating in social, economic, and political activities and processes, including international development policy, practice and research. For example, of people with schizophrenia, research shows 29 per cent experience discrimination in either finding or keeping a job and 42 per cent feel the need to conceal their condition when applying for work, education or training.² These kinds of exclusion serve to reinforce the disproportionately high number of people living with disabilities among the poorest of the poor.

The relationship between disability and exclusion is relatively well understood. Numerous studies have shown that persons with disabilities are subject to discrimination.³ For example, they are excluded from the education system, leading to a lack of skills

and lower self-esteem. This reduces their income-generating opportunities, making it more likely that they live in chronic poverty, leading to further exclusion. However, what is less well understood is the reality of this relationship as it is lived by real people; the experiences of social, economic and political exclusion from the perspective of persons with disabilities. It is this gap that this research sought to address.

This gap matters because the voices and perspectives of persons with disabilities provide a picture of their reality and how they see exclusion affecting them. As stated in Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is important that there is “full and effective participation and inclusion in society”. Article 33 relates to national implementation and monitoring of the Convention and states that, “Civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process.” (UN General Assembly, 2008⁴). This research provided an opportunity for persons with disabilities to give their perspectives on how their rights are – or are not – being upheld in one country, namely Bangladesh.

The research sought both to understand and address the social, economic and political exclusion of persons with disabilities and older people by using participatory methods to understand what persons with disabilities and older people understand as the causes of their social, economic, and political exclusion.

3.1 Persons with disabilities in Bangladesh

It is difficult to state the prevalence of persons with disabilities in Bangladesh precisely as different surveys have measured disability differently and there is no internationally agreed figure. However, globally it is known that the cost of disability due to lost income resulting from a lack of schooling and employment, both of persons with disabilities and their carers, is estimated at US\$1.2 billion annually, or 1.7 per cent of gross domestic product.⁵

3.2 Older people in Bangladesh

Bangladesh is the world's seventh most populous country, with a population, according to the last census in 2011, of 150 million.⁶ It is also experiencing rapid demographic transition; life expectancy is increasing while birth rates are falling. The share of the population above the age of 60 is growing at a rapid rate, from 1.9 million (4.4 per cent) in 1951 to 9.4 million (6.6 per cent) in 2007. This number is expected to increase to 14.6 million (about 9 per cent) by the year 2025. More of those who cross the age of 60 are now expected to live to 75 or beyond.⁷



©Peter Caton/Sightsavers

¹ UNESA (2011) *World Population Prospects: The 2010 Revision*, New York: UNESA

² Thornicroft, G., Brohan, E., Rose, D., Sartorius, N. and Leese, M. (2009) Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional study, *The Lancet*, 373(9661): 408-415

³ Yoe, R. and Moore, K. (2003) Including disabled people in poverty reduction work: "Nothing About Us, Without Us", *World Development*, 31(3): 571-590

⁴ UN General Assembly (2008) *UN Convention on the Rights of People with Disability*, New York, UNGA

⁵ World Health Organization (2011) *World Report on Disability 2011*, Geneva: WHO

⁶ Bangladesh Statistics and Information Division (SID) www.sid.gov.bd/statistics/bangladesh-at-a-glance-census-2011/

⁷ www.helpage.org/where/bangladesh



4. Research design and methodology

This report has been generated by both the community peer researchers and the NGO peer researchers. The methods were developed by IDS in consultation with local staff of Sightsavers, HelpAge International and ADD International, and were discussed and refined with the peer researchers themselves.

The peer researchers helped design the story prompts and undertook all the story collection. They then carried out the analysis of the material collected. They were supported in this process by a small team of facilitators from Sightsavers Bangladesh, HelpAge Bangladesh, ADD Bangladesh, and IDS. The main report comprises the stories collected by the peer researchers and their analysis.

4.1 Our definition of disability

Disability is the broad term used to describe the barriers that individuals face as a result of an impairment, or of limitations to their activities, or an inability to participate fully in society. These barriers generally fall into three categories:

- environmental, e.g. inaccessible buildings and services
- attitudinal, e.g. stereotyping, discrimination and prejudice
- organisational, e.g. inflexible policies, practices and procedures.

This research therefore adopts a diverse understanding of disability, encompassing, for example, someone born with a congenital condition such as cerebral palsy, or a person who has damaged their leg in an accident, or someone with schizophrenia, or an older person with dementia, or someone with a chronic illness.

4.2 What is participatory research?

Participatory research aims to break down the divide between researchers and the researched. It is research WITH people, not ON people. The participants are the researchers themselves and they pursue answers to the questions and problems that affect their daily lives. Participatory research is not guided by questions from external researchers. It is based on the stories that people want to tell. In participatory research the analysis is done by the participants, and the implications of the analysis are determined by the participants.

4.3 What is peer research?

Peer research is a form of participatory research. In it, the researchers are people rooted within particular constituencies or communities and they are supported as they generate research with their peers.

Two groups of peer researchers were supported to undertake this study:

- community peer researchers: These were persons with disabilities and older people from one of two communities – Bhashantek slum in Dhaka, and the Jhilonja area of rural Cox's Bazar, in the southeast of Bangladesh.
- NGO peer researchers: These were people who work with persons with disabilities and older people in local Bangladesh NGOs.

The peer researchers were asked to collect stories from “people like you”. Therefore, the community peer researchers spoke with persons with disabilities and older people in their respective communities; the NGO peer researchers spoke with



staff of local NGOs who work with persons with disabilities and older people.

All the peer researchers helped to design the story prompts and identified peers within their communities or constituencies to collect stories from. They gathered the stories and collectively analysed them, and their analyses and quotes from the stories form the body of this report.

4.4 Collecting stories

Prompts were used to collect stories rather than interview questions to encourage participants to share their stories. This also ensured that issues important to participants were not pre-empted. The prompts were open-ended and follow-up questions asked about the story told. Stories rather than visual methods were used to ensure that those who were blind or who had low vision could engage equally.

4.5 Site selection

A community in an urban neighbourhood (Bhashantek) and another in a rural area (Cox's Bazar) were selected as sites for this research so the perspectives of persons with disabilities and older people living in both kinds of communities could be understood. The two particular communities used were chosen because both are characterised by relative poverty and experience a particular problem

or issue facing persons with disabilities, mental health problems, and/or older people.

The NGO peer researchers were also recruited using geographical criteria (see below), to ensure they represented NGOs working in diverse geographical areas of Bangladesh.

4.6 Selection of peer researchers

Staff from Sightsavers, HelpAge, and ADD identified and recruited the peer researchers. They identified five community peer researchers from Bhashantek, six community peer researchers from Cox's Bazar and seven NGO peer researchers.

The selection criteria for the community peer researchers were:

- persons with disabilities and older people
- people living in poverty and/or experiencing exclusion
- people living in the neighbourhood/community
- a representative balance of the different interests or groups within the communities
- a balance of women and men, and type of disability.

Selection criteria for the NGO peer researchers were:

- a diverse range of partners across Sightsavers, HelpAge and ADD (i.e. a mix of participants from different associations and local NGOs)
- a balance of women and men
- a diverse geographical spread
- experience of using participatory methodologies
- people with a strong network of peers with whom to conduct research.

4.7 Ethics

All the peer researchers were given clear guidelines to ensure the people they spoke with gave informed consent to use their stories.

The community peer researchers introduced themselves. They explained they were collecting stories from persons with disabilities and older people to be used in a research study for Sightsavers, HelpAge and ADD. They clarified that the results of this study were going to be used both in Bangladesh and internationally. Consents were either recorded or witnessed by a third person whose name and contact details were noted. Informed consent was obtained from the parent or legal guardian of participants under 18. All the names of those whose stories were collected by the community peer researchers have been changed.

The NGO peer researchers followed the same procedures. The names of the participants whose stories they collected have been used in this report, but any people these participants named have been made anonymous to protect their identities.

4.8 A note on representation and generalisation

The findings from this research cannot be considered representative of all persons with disabilities and older people in Bangladesh. This is usual for a participatory research study, and is a result of sample selection not being random and sample size not being large enough to be statistically significant. However, within the study the perceptions and opinions of persons with disabilities and older people from two communities (one rural and one urban) could be triangulated with the perceptions and opinions of staff working in more than 40 different organisations. This ensured the findings are robust.

4.9 Research design and planning workshop: November 2012

In November 2012, two three-day research design and planning workshops were held, one for the NGO peer researchers and another for the community peer researchers. The principles of participatory research were introduced, the objectives of the research explained and everyone's expectations reviewed. The peers whose stories would be collected were identified and discussions held about the story prompts, how the stories were to be collected, ethics, and the importance of informed consent. The documentation and safe storage of the stories was also discussed.

Finally, the peer researchers practised collecting stories. The NGO peer researchers collected stories from staff in the ADD office, while the community peer researchers practised in three rounds: first, they collected stories from each other and analysed them; second, they collected stories from community members from Bhashantek slum; and, finally, they collected stories from random people they met on the street. They analysed the difficulties they faced after each of these rounds and explored the ethical issues such as informed consent.

The prompt questions agreed for the community peer researchers were:

- Tell me a story about a challenge you have faced as a person with a disability or an older person.
- Tell me a story about something that happened to you because you are a person with a disability or an older person.



The prompt questions agreed for the NGO peer researchers were:

- Tell me a story about how economic, social or political changes have impacted/ influenced a person with disabilities or an older person you know.
- Tell me a story about a person with disabilities or an older person who is unable to live the life you think they would want to.
- Tell me a story about a person or group of people who you have been unable to support.

At the end of the workshops the facilitators provided the peer researchers with guidelines (See Annex 1). The community peer researchers were asked to collect stories from 36 peers in each community. The NGO peer researchers were asked to collect stories from nine peers each.

As some community peer researchers were people who are blind or have low vision, or who are illiterate, they decided to collect the stories in twos or threes. A volunteer was recruited in each community to

accompany the community peer researchers, to record the stories on a digital recorder and to type up the transcript. These volunteers were not allowed to interfere in the story-collecting process.

4.10 Mid-term workshop: January 2013

In January 2013, a two-day mid-term workshop was held in Cox's Bazar for both groups of community peer researchers, and a one-day mid-term workshop for the NGO peer researchers was held in Dhaka. The purpose was to review the progress of the story collecting and provide support to the peer researchers if needed.

The community peer researchers reported that with some peers they had to explain the prompts several times before they understood what was wanted from them. As a result, many of the interactions ended up being questions and answers rather than open-ended story telling. Despite this, the community peer researchers felt they had collected interesting and relevant information about the perspectives of their peers.

The community peer researchers also raised concerns about speaking to persons with intellectual impairments. In each case, the community peer researchers asked permission of the person's family members and a family member told the stories. The community peer researchers said that in each case the person with intellectual impairments was not capable of telling their story. While this does not necessarily make these stories invalid, as the perspective of a relative of someone with an intellectual impairment is interesting, it does raise a question of legitimate representation. It also raises the fact that many people with intellectual impairments are assumed to be unable to speak for themselves.

The NGO peer researchers felt their first and second prompts were too similar and often elicited similar stories. The first prompt, about the effects of economic, social and political trends on people, was often interpreted as being about the economic, social and political situation of the people themselves. The last prompt, about a person they

have not been able to support, often elicited a response about a problem of a lack of funding – unsurprisingly, given that most of the peers work or volunteer for an NGO or PWD organisation. It was agreed that the researchers could try asking different prompts to try and elicit a variety of stories. They could also ask their peers to talk about experiences of other organisations for the third prompt, as the peers may be more willing to talk about difficulties faced by other organisations rather than their own, as well as ask more probing questions for this prompt, such as whether other reasons exist for not being able to support people other than a lack of funds.

4.11 Research analysis workshop: April 2013

In April 2013, a five-day research analysis workshop took place in Dhaka. The community peer researchers and the NGO peer researchers worked separately for the first four days to analyse the stories they had collected. On the final day, all the peer researchers came together to share their analyses and discuss similarities and differences.

4.11.1 Community peer researchers

The community peer researchers analysed 37 of the 70 stories collected. The stories were divided into categories and small sections randomly selected for analysis. The community peer researchers worked in four groups, two groups from Cox’s Bazar and two from Bhashantek, and they analysed the stories over two days. Each group had at least one person who read the stories out to those who were blind or who had low vision or were unable to read. With more time and budget, all of the stories would have been reviewed. The table below shows how many stories were analysed and who they came from.

Table 1: Participants offering stories for analysis

| Participants | Total |
|---|----------------------------|
| Older women | 8 |
| Older men | 8 |
| Women with physical disabilities | 3 |
| Men with physical disabilities | 3 |
| Women who are blind or have low vision | 3 |
| Men who are blind or have low vision | 4 |
| People with speech/hearing impairment (all men) | 4 |
| Women with intellectual impairment | 2 |
| Men with intellectual impairment | 2 |
| Total women and men | 16 women 21 men |

For each story, the community peer researchers were asked “What are the factors/issues that you think are important in this story?” They wrote each factor or issue on a Post-it note, which was then read out before being clustered with similar factors or issues on flip chart paper. So, for example, all the Post-it notes with the issue “not being able to afford medicine or treatment” were clustered together.

The IDS researchers selected the 12 issues that arose most frequently in the stories i.e. those that featured on the most Post-it notes. The community peer researchers agreed these issues were the most important. As not every story could be collectively analysed, the peer researchers were able to suggest factors or issues they had heard often in stories but that had not arisen in the 37 stories read through. In this way, they added the issue of lack of special services/facilities for persons with disabilities and older people.

The community peer researchers then worked in groups to discuss each issue. They were asked to

draw on examples from the stories they collected and their own experiences in order to answer the following questions:

- Who does this affect?
- Why does this happen?
- What can we do to change this?

4.11.2 NGO peer researchers

The NGO peer researchers were asked to read through a selection of stories. They were then divided into three groups so they could focus on the following questions:

- Is there anything that you think is important in this story? Discuss why.
- What is the issue that it raises for persons with disabilities and older people?

The peer researchers then wrote down each issue identified on a separate Post-it note and stuck the issues on a large map made of eight sheets of flip chart paper taped together. On the back of the Post-it notes, they wrote the reference to the story that the issue came from (to ease story and quote identification for analysis and writing up, later). As the Post-it notes were written in Bangla, they were simultaneously translated and an English version also placed on the map.

The NGO peer researchers selected parts of stories which illustrated issues and clustered the Post-it notes as they placed them on the map. For example, “A woman who was raped was forced from the village because the man who raped her was the son of a powerful person in the village”, was placed next to the rape of a girl who worked in a clothing factory by her manager because the manager was protected by the owner and the family was also forced to leave. These were clustered with other stories about rape where justice could not be obtained. These clusters formed the categories for discussion by the group which resulted in the analysis.

With each round of stories read, more Post-it notes were layered on the map. This resulted in more than



©Snigdha Zaman/ADD

10 main lines of inquiry, which were discussed and analysed over more than a day. In the analysis, the NGO peer researchers were asked:

- What was important and why?
- From their experience, was it a common pattern?
- Were there stories that were surprising, and why?
- How did they explain what was in the stories?
- What did they think needed to be done about it?

4.12 Verification workshop: June 2013

All the peer researchers reviewed the report once it was drafted by the facilitators at a verification workshop in June 2013. The peer researchers read the report and verified that it was an accurate representation of their discussions and analysis. Modifications were made when needed.



5. Analysis and discussion

Both the community peer researchers and the NGO peer researchers acknowledged very similar issues. These are discussed and analysed below. Two issues were only identified by the NGO peer researchers: rape and sexual harassment; and the role of NGOs. These are explained at the end of the current section.

5.1 Accidents and disasters

5.1.1 Accidents or natural disasters causing disability

In a number of stories heard, persons with disabilities explained they became disabled as a result of an accident or a natural disaster. For example, one mother explained how her son became intellectually impaired:

“It happened when he was six or seven ... there was a big hole in front of my house which he fell down. After he was rescued he became like this ... He can't talk properly ... he suffers from convulsions every few days. He can't find food, he doesn't know how to search for money. If people give him four or five taka for a whole day's work, he doesn't say anything ... He can't differentiate between one taka and 10 taka ... He fell from a CNG [motorised rickshaw] a few days ago ... We feel bad, he can't understand anything. We couldn't arrange a marriage for him. Now he just sits in his own excrement.”

Mother of Mishkat, aged 45, Cox's Bazar

A woman with a physical impairment also shared her story about the accident and lack of medical treatment that caused her disability:

“I was chasing after my son and my foot got caught in a doorway. As soon as I tried to get up I started screaming and shouting ... everybody in the road gathered and started calling my mother who started calling my aunt ... Then everybody came running and asked, 'What's the matter, what's the matter – why are you lying down?'

I was crying so much that I couldn't even speak or move. Then, people picked me up. My body was shaking and legs trembling. I couldn't say anything because I was unconscious by then ... The kaviraj [local traditional healer] treated me. The incident happened in the village. They ground some herbs and told my aunt to bind them around my leg.”

Mila, aged 65, Bhashantek

5.1.2 Disability and older age contributing to higher risk of accidents

Persons with disabilities and older people are at higher risk of accidents. For instance, people with visual impairments risk being hit by a car if they cross the road alone while older people can be physically weak and fragile. An older woman shared her story:

“I used to work as a housemaid ... I can't anymore because of the weakness in my legs. I don't have the strength anymore. My feet feel numb and when I try to walk I bump into things and fall over. I broke my leg. Look at the scars ... [This has happened] many times. Just a few months ago I broke my leg ... [it's happened] two or three times.”

Sadia, aged about 80, Bhashantek

Persons with disabilities and older people are also more likely to be injured or killed in a natural disaster. During floods, they find it difficult to reach shelters because they sometimes cannot move as fast as others to find a safe place. Other people become busy with their own safety in these situations, often leaving the elderly in the home to take care of the belongings.

5.1.3 What should be done?

Raise awareness about disasters

We need to raise awareness about natural disasters through the media. We need a campaign to warn us and explain how to prevent and cope with disasters. When a disaster signal comes, the authorities should prioritise relocating people with disabilities and older people. Information and training on disasters needs to be available in Braille, sign language and pictures. They should also raise awareness for members of the community to look out for and rescue older people and people with disabilities. Local government needs to distribute information about what to do in a natural disaster.

Raise awareness about accidents

Additionally, we need a campaign to raise awareness of accidents that can cause disability. Older people and people with disabilities need information, but also the general public and government must understand risks. NGOs should raise awareness about how to reduce the risk of accidents and how to prevent accidents, for example safe movement and traffic-safety awareness training. Perhaps we could have an accident prevention day? We should encourage people to use bridges and not cross roads.

5.2 Access to education

5.2.1 Lack of money and stipends

Many poor persons with disabilities and older people cannot afford to pay school fees for dependent children, said the community peer researchers. There are education stipends for children with disabilities, but they are limited in number and sometimes corruption surrounds their distribution. The decision as to who gets one is made by central government, which has a list of children with disabilities in each district.

Nazma Akter Rasheda, a community peer

researcher from Cox's Bazar, said that in her old school there were two children with disabilities, one from a rich family and one a poor one. The father of the boy from the rich family was friends with the headmaster, so the headmaster gave a stipend to his friend's son. When the poorer boy failed to receive support, Nazma's disability self-help group and [the NGO] SARED intervened, but the headmaster still refused to support the poor boy. Local government has since told the headmaster that in future a poorer boy should receive any available stipend, but the poor boy in this particular situation is still paying fees.

The community peer researchers said that education is free, but every year parents of students still need to pay from 400 to 3,000 taka a year for things that are not included (school bags, school uniform pencils, eraser, sharpeners, etc.). The researchers believed parents should not be charged.

5.2.2 Lack of infrastructure and facilities

The NGO peer researchers agreed that children with disabilities rarely access education. Those with hearing and speech impairments, or who are blind, or have low vision suffer the most because it is difficult for them to follow lessons. Teachers often teach by reading out texts, so if children cannot hear or see they cannot learn.

The situation has improved for children with disabilities, but not enough, they said. One example of improvement they gave is the introduction of ramps in all government primary schools. The government has also included disability in teacher-training curricula. The NGO peer researchers explained while this is not good enough, at least government has taken the initiative. They pointed out that there are very few specialised schools for children with disabilities and these are not accessible to people who are poor. There are one or two schools that provide free education, but competition for a place is high and the very poor, who live in slums, do not know that these services are available. In rural areas, specialist schools are only available at divisional level and it is not possible for children with disabilities to get to them.

In addition, these are residential schools with costs attached so, again, the poorest cannot access them. Under the Department of Social Services there are schools for children who are blind or have low vision in 64 districts, but many of these schools are not functioning. Either there are no teachers, or the teachers are not working effectively, or people are not informed that the schools exist.

The community peer researchers stated that many children with disabilities are unable to go to school because of their physical impairments. For example, classes may be up stairs. Teachers also lack awareness about disability and there is a lack of appropriately trained teachers, for example those who can teach in sign language. Central government is committed to enrolling all children in school but monitoring is weak, they said. Local-level officers do not monitor school enrolment and are unaware of the rights of children with disabilities. There is no Braille or sign language so the children themselves do not want to go to school.

Many classes are 100 students per teacher and 60-70 is common.

The community peer researchers added that government is not supportive. There are insufficient schools and the teacher-student ratio is too high. The standard ratio is 45 students per teacher, but many classes are 100 students per teacher and 60-70 is common. Given this situation, teachers avoid weak and slow-learning students (including students with disabilities).

5.2.3 Disability discrimination and bullying

A lack of disability awareness means there is discrimination, the peer researchers said. Children with disabilities are sometimes not admitted to school because it is believed other children would be scared of them. When they are admitted, they can be bullied and not treated with respect.

A woman told the peer researchers the story of her granddaughter who has an intellectual impairment:



©Tim McDonnell/Sightsavers

“When she grew up, her parents enrolled her in the school. Either her father or mother used to drop her at the school, but she wanted to go to school by herself. But when she went alone, children used to tease and beat her. She couldn’t concentrate on class work for long. She studied as long as the teacher forced her to study. Even in school her classmates disturbed her in every way. In response, she quarreled with them and returned home alone. She can’t bath by herself. Someone has to take care of these things. She can’t eat properly. Even if she gets hungry, she doesn’t ask for food. If her mother reminds her, she eats. Sometimes she cries out while sleeping. She wants to study at home and sits with her books. But when she can’t read she gets frustrated and leaves the lessons. Everyone is worried about her future. After all, she is a girl and how will she survive?”

Grandmother of 13-year-old Abida, Cox’s Bazar



5.2.4 Gender discrimination

Families are less likely to send girls with disabilities to school because of gender discrimination, the community peer researchers said. They explained there are insufficient schools for girls and it is unsafe for them to go to school, especially girls with disabilities. In rural areas, parents have to work so they have little time to accompany their daughters to school. The NGO peer researchers added that the families of girls with disabilities feel insecure about sexual harassment so are even more reluctant to send their daughters to school.

Samira Khatun, an NGO peer researcher, said her family had always encouraged her. She has been in higher education for three years. But village people have a negative attitude because she lives away from home. She said they do not believe she leaves home for education only and this is embarrassing for her. A few days ago, she reported, she met two boys. One said: “Where is she going? We heard she was doing education – but God knows what she really does.” Samira said that even those who support girls’ education at primary level change their position at secondary level. They are more

interested in their daughters getting married – to get rid of her and to get a dowry.

The NGO peer researchers said that the 64 schools for children who are

The 64 schools for children who are blind or have low vision are only for boys.

blind or have low vision are only for boys. There are no hostels for girls to live in while at school. Some specialised private initiatives may have opportunities for girls but this is rare. Only five divisional schools have provisions for both boys and girls.

5.2.5 Unsupportive family

If parents are illiterate, they may not understand the value of education for their children with disabilities, said the NGO peer researchers. They may prefer to send their children out to work or out begging. Parents of children with disabilities said someone needs to be with their child at all times and they do not believe the schools will provide sufficient care. Besides, some families do not believe their children with disabilities are capable of learning. Md Al Amin, an NGO peer researcher, said after he received an education and started working, he was held up by his village as an example to younger people. He related the story of a school in a village where he worked, which had no children with disabilities attending it. As he knew the women’s group in the village, he introduced two children to the group, one with a hearing impairment and one with low vision, to show how these children were capable of learning. One child used a hearing aid and the other a magnifying glass. After seeing this, the mothers started taking their children with disabilities to school, Md Al Amin said.

5.2.6 What should be done?

Provide for and promote inclusive education

There are school management committees formed by élites and civil society. These should be made aware of the rights of children with disabilities and they should monitor the enrolment rates of children with disabilities. Additional accessible facilities and adapted teaching materials are needed. Non-disabled students get free books, but students who are blind or have low vision have to pay for Braille books. Braille must be introduced into schools and teachers trained in Braille. We need to provide hearing aids, and white canes.

Donors should put pressure on the government to promote inclusive education. There are special integrated schools for students who are blind or have low vision, but we need more. It is the responsibility of government to set up special schools. But NGOs also have a responsibility – through advocacy for example. NGOs and the government should work together.

Ensure jobs for educated persons with disabilities

Education relates to employment. If your education does not help you get a job, the next generation will not be inspired to get educated. So there needs to be job opportunities for people with disabilities who are educated.

Work with families

Awareness-raising activities should be conducted among families. In remote rural areas people do not believe that people with disabilities can learn. They have never seen this so we need to show examples.

If we really want to send children with disabilities to school we need to provide their families with livelihood options. We need incentives. For example, there was a programme which gave a stipend to the children so they could go to school. It also offered a loan to the family so parents could fill the financial gap that the child left by not working anymore.

5.3 Livelihoods

The issue of a lack of a livelihood featured in almost all the stories collected by the peer researchers.

5.3.1 Difficulty finding a job due to disability

There are too many people in Bangladesh, the community peer researchers said, making it difficult for everyone to find a job; persons with disabilities find it even more difficult. Persons with disabilities who have had no education and whose

families do not support them have to beg. An older woman with a physical impairment told the peer researchers:

“I used to work, but since I broke my legs I’ve had to beg. Otherwise I go without food ... I have to. Without begging I wouldn’t be able to live ... I have no choice but begging.”

Laboni, aged 70, Bhashantek

The mother of a boy with an intellectual impairment told them:

“[My son] can’t talk. He can’t communicate, even to tell me he wants to eat. He begs from people, asks for food or anything. He’s had this problem since childhood.”

Mother of 18-year-old Akid, Bhashantek

Even persons with disabilities who have an education but no money to invest in a business are forced to beg. Salamot Ullah, one of the community peer researchers from Cox’s Bazar, who has a physical impairment, explained that he was asked for a 50,000 taka bribe when he applied to be the Principle of a madrasa (an Islamic school). Eventually, he was given an assistant’s job, but his salary was irregular and not the same as other teachers. Difficulties were made for him and eventually he left. He said:

“Qualified disabled people can’t afford these bribes. People without disabilities have alternative options if they can’t get a job. They can be self-employed. But people with disabilities don’t have as many alternatives. People with disabilities can’t influence powerful people. In general, people have negative attitudes about disability, so they don’t employ us.”

Salamot Ullah, Cox’s Bazar, community peer researcher

The NGO peer researchers said that employment is a number one priority for persons with disabilities. Those who find work also find positive regard from their families and communities. Many stories told how people who had been helped into livelihoods gained greater acceptance. For example, several stories illustrated a lack of belief in what persons with disabilities can do until they started working.

One story stated that “with income, acceptance increases”. Another story told how a girl gained greater acceptance in her family after she got a job in a garment factory. Almost all the positive stories of persons with disabilities who found a way out of begging involved some sort of small shop:

“Now, he works with his sewing machine. He opened a shop, and there he sews with the machine and earns money to support his family. When he started to sew clothes the villagers didn’t want to give him work. Gradually, one or two people gave him clothes to sew and they saw that he did the work well. Others also started to give him work and understood that he can do this work.”

Nazrul Islam, NGO story



©Snigdha Zaman/ADD

Many organisations just hire orphans and persons with disabilities are left behind.

The community peer researchers agreed and stated that vocational skills training for persons with disabilities and adult education was needed to encourage self-employment.

However, even when training works well, they said, life in Bangladesh is so precarious everything can fall apart in an instant. One story told how a man with disabilities was trained to work with poultry and provided with 15,000 taka for investment to start a business. Everything was going well until a cyclone in 2007 damaged his property. He returned to his former, poor life and is not interested in taking another loan because of the difficulty in paying it back.

The NGO peer researchers added that those living in poverty do not have time to support livelihood training for their children. They told the story of how one NGO arranged for a group of children with hearing and speech impairments to be trained in making and then marketing paper bags. On the day of the training, only six children turned up. People who are poor cannot afford to give up their time for training, they explained. In any case, the teacher doing the training knew sign language but not sign language in the right dialect to communicate with the group.

Ten per cent employment quotas have been created by the government in the public sector so persons with disabilities and orphans are hired. However, the reality is that many organisations just hire orphans, said the community peer researchers, and persons with disabilities are left behind. In the leading industry, the Bangladesh Garment Manufacturers and Exporters Association (BGMEA) has a policy for a 5 per cent quota for persons with disabilities. ADD has an agreement to supply skilled persons with disabilities under that quota, but it is difficult for them to find the right people to do this work. Many garment factories have 15, 16 or 17 floors and

no lifts so it is difficult to work there if you have a physical disability. However, garment factories prefer people who have hearing or speech impairments because they think they will work better, and because they can climb stairs.

5.3.2 Begging as a livelihood choice

The NGO peer researchers heard many stories about begging. For most persons with disabilities begging is not an option; it is the only way to obtain food and survive. There were stories of older people who could not get jobs and of persons with disabilities people believed were unable to work. The NGO peer researchers said countless people do not receive pensions, but for those that do, 300 taka a month was simply not enough to live on. In general there was a perception that there are no livelihood options for people with no limbs.

For some, begging was seen as a good living and one story talked of begging as an addiction. Begging was seen as less laborious and more beneficial than other work. The NGO peer researchers' group discussion noted how one man with a disability was provided with a teashop so he could sell tea, but he decided not to keep it going because he could earn more by begging.

The community peer researchers said that poorer persons with disabilities and older people go to the cities to beg as it is hard to make a living begging in rural areas. People who live alone in rural areas ask their neighbours for money because they cannot get enough from begging. For example, it is difficult to beg in the Cox's Bazar region as it is hilly and

houses are remote. When people climb a hill and go to a house there is no guarantee they will get money, and it is difficult to climb a hill if you have a disability. The community peer researchers added that persons with

For most persons with disabilities: begging is their sole means of surviving and finding food.

disabilities; whether or not they are educated, cannot find jobs because people do not want to hire them.

5.3.3 Access to affordable credit

Many NGOs offer loans, but while the NGO peer researchers heard stories of people who managed to set up businesses with their loans, there were also stories of people who got into serious debt. For example, some people borrowed money to tide them through short-term crises, but they ended up with long-term debts with no lasting solutions to their problems. There were a few examples of loans making a difference, but mostly people were not given enough money to start a successful business, and so they ended up spending the money on essentials. Additionally, many older people do not get loans:

“A number of people can do bamboo and rattan-related works, make baskets, especially nets which are used to catch crabs. They need some capital for doing these works, but because they're too old they can't take a loan from any NGO or government bank because these people believe that they'll not be paid back when the old people die.”

Kya Swichen Rakhain, NGO story

For others, the money borrowed simply was not enough to make a difference:

“We have some groups where there are many physically impaired people. We gave them tricycles and money to do business. However they spent all their money and are back doing their old job again. We helped them as much as we could to pull them out from their begging occupation. They took the money to run a tea-and-biscuits business. However, they spent all of their money and began to beg again by using our tricycles.”

NGO peer group researcher

The NGO peer researchers heard a story about a 60-year-old woman who had managed to find a job through the help of her chairman:

“The chairman managed an elderly allowance card for her. She received the money in a lump sum after six months. After getting the money she opened a shop to sell little odds and ends, biscuits, peanuts, pickles etc. After seeing this, the elders committee gave her 600 taka by collecting from their savings and told her to repay it on a monthly basis. The elders started to do their business with her shop to increase her sales and their profit. Now she attends meetings and as her status has increased after joining the elders committee so her courage has increased.”

Hosne Ara Khuku, NGO story

It is very difficult for persons with disabilities and older people to obtain loans from a bank or NGO.

Often relatives of persons with disabilities exploit the loan system. The NGO peer researchers' group discussion heard how the parents of one girl with a disability received a loan because of their daughter's disability. However this resulted in the disability allowance

she received being cut, even though she had not received any of the loan money herself.

The community peer researchers also thought access to credit was a problem. They said banks will not give persons with disabilities and older people loans while, NGOs tend to give them to people without disabilities and young people. There is a belief that older people do not earn and persons with disabilities cannot work, so neither can pay the loans back. Various initiatives have been created but they are not always genuine. For

instance, the government agreed to give loans to persons with disabilities but asked 25,000 taka as a deposit which is not realistic. Some rich people also offer loans but the interest rate is too high.

Other systems exist: The agricultural bank lends 10,000-15,000 taka to farmers. The bank collects the money from the farmers based on a percentage of their profits. There is also a village system, in which people can borrow money and agree to pay a certain amount back at a fixed rate of interest. If repayments cannot be made, the interest goes up. There is a mortgage system too where land or cattle can be mortgaged for cash. A man with a visual impairment told a community peer researcher:

“I started my own business making straw with a loan from an NGO, and then later from the local government. I have to pay interest on the loan from the local government and I've had many problems with this loan.”

Abir, aged 40, Cox's Bazar

The community peer researchers explained that sometimes people find loans from persons who are blind or have low vision, and then they fail to pay the money back or try to con the person with visual impairments, “because they think we can't see and they can do this to us”.

5.3.4 Pensions and disability allowance

The government has limited resources to provide stipends, but it is trying, the peer researchers said. However, there are biases and local government officials provide support to their relatives or people from the same party. Also, people are unaware of what they are entitled to, there are fewer resources for persons with disabilities than for others, and both persons with disabilities and older people do not know how to get the stipends.

They explained that the Vulnerable Group Development (VGD) provides free rice and flour, which widows can access. At age 65, there is also a pension of 300 taka a month, which people should receive on top of their disability allowance,

but often older people only get one allowance. For four years the disability allowance has not increased, they said, nor the number of people receiving it. The amount is insufficient and the government says it will increase the allowance, but it never does. A realistic amount to live on would be 2,000 taka per month in Bhashantek. Another problem is that people have to pay bribes to get the forms for pensions and disability allowances. One community peer researcher from Bhashantek said:

“[Persons with disabilities] need to get a higher allowance. For 10 taka a day we can only get a cup of tea. I’m a self-help leader. People ask me how to get the disability allowance and I can’t answer them. There aren’t enough allowances. I collected a disability allowance form and photocopied it for 20 people, but the government officer wouldn’t accept the photocopied version. Family members were angry with me because they didn’t get the allowance. The present Government has stopped the distribution of forms now. The pension for older people and the disability allowance is too low, 300 taka per month is not enough.”

Selina Begum, Bhashantek, community peer researcher



©Tim McDonnell/Sightsavers

5.3.5 What should be done?

Provide training

There are successful initiatives for getting people into employment. The garment industry is very strong here. One NGO thought, “Why don’t we try to get people with disabilities jobs in the garments industry?” At first, owners were unconvinced. But they trained 12 people and it worked very well. After this example, other factories became interested. So far they have trained more than 300 people. NGOs can take this kind of initiative, like ADD who provides workers for big shoe shops.

Increase quotas

The jobs quota in the public sector should only cover persons with disabilities and there should also be a quota covering the private sector. For jobs in the public sector, the educational level requirement for persons with disabilities within the quotas should be lower.

Facilitate loans and increase stipends

Under the Ministry of Social Welfare, people with disabilities can get 5,000 and 10,000 taka loans, but the government cannot afford to give this to everyone. In consequence, the procedure is very selective. The loan should be given to more people. The number of stipends also needs increasing. The government needs to increase the amount of tax to pay for this. For example, if you start a business, you should have to pay a licence.

Promote awareness and transparencies

Greater awareness is needed about disability and ageing. Local government and social workers need lists of people with disabilities and older people. This would make it easier to plan how to distribute allowances. There should be a transparent system to show how the money is distributed. The different committees could discuss how this process can be more transparent. The District Social Welfare office should lead this process, while it should be monitored by the District Disability

Federation. NGOs that work with persons with disabilities and older people should advocate with social welfare officers and the Ministry of Social Welfare for these changes.

Provide opportunities in rural areas

There is a difference between opportunities in urban areas, where there is more industry, and rural areas. There is a need to invest in industry in rural areas. Some women who do not have disabilities do handicrafts and work in co-operatives. Women with disabilities could also do this to provide an income.

5.4 Medical treatment

5.4.1 The cost of treatment

Stories told to the community peer researchers revealed that older people and people with disabilities find it difficult to pay for the medical care they need. An older man from Bhashantek slum shared his story:

“There’s no money, so what will I use to have treatment? They take money for everything. For my nose operation they said it would cost 10,000-20,000 taka. Now I can’t be cured because I lack money. If I had money, I could have treated myself ... I could breathe properly.”
Mamun, aged 65, Bhashantek

One of the community peer researchers from Bhashantek, Mohammad Akkas Molla, who has a visual impairment, explained that when he went to a government hospital he needed a ticket for 20 taka. Then the doctor asked him to pay for the x-ray. He said:

“For just a [hospital] appointment, it costs 20 taka, but any tests or medicine are extra. We can’t afford it and we come back without being treated. For example, you have to pay more than 500 taka for a bag of blood. If there’s an accident and we need emergency health care the government

hospitals do take care of us, but they’re a long way away. Private clinics don’t treat emergency cases.”
Mohammad Akkas Molla, Bhashantek community peer researcher,

The cost of medical treatment can also prevent older people and persons with disabilities from seeking medical care. The mother of a girl with multiple physical and intellectual impairments shared her experience:

“My daughter can’t speak. She can’t hear. She can’t go out of the house. She beats people, she’s violent and people judge her. I’m worried, but what can I do? She’s been born into a poor family ... All day I worry, what will happen to her after my death? ... She can’t be treated because we are poor. Her father has no work.”
Mother of 26-year-old Shoma, Cox’s Bazar

It is not just the cost of treatment for an older person or a person with disabilities that causes problems in accessing care. One mother of a boy with a speech impairment explained how the cost of treatment for his sick father meant she was unable to take her son for the treatment he needed:

“We didn’t [see a doctor] because we hadn’t enough money. [My son’s] father was seriously sick then, and has been sick these last three years. We’ve spent a lot of money on his treatment. Hardly a day passes without borrowing [money] from people. That’s why we haven’t taken my son for treatment.”
Mother of seven-year-old Parvaz, Cox’s Bazar

A lack of access to government services can also mean the cost of treatment increases and makes it more difficult for older persons and persons with disabilities to access health care. Government hospitals are very far from people’s homes in Bhashantek, the community peer researchers said,

and the private clinics nearby are very expensive. Private clinics will not give older people free treatment. An older woman told them:

“I suffered a stroke a year ago and since then I’ve been very sick. I wasn’t even able to speak. But with the help of other people I’ve gradually felt a little better and now I’m just surviving, somehow... I don’t have any money. How can I see a doctor? My legs and hands are very weak. I feel pain. There’s no strength left in me.”

Rupa, aged 65, Bhashantek

5.4.2 Corruption and discrimination

There are too many patients and too few beds in government hospitals, said the community peer researchers. There are always long queues to get treatment and medicine, and brokers must be paid to jump the queue. This means that poor persons with disabilities often go without treatment. They added that there is also discrimination, with younger

people and those with influence getting quicker treatment. People who support the party in power get treatment first. There are no separate queues for persons with disabilities or older people.

The NGO peer researchers said that in government hospitals, brokers and agents from different clinics and private organisations try to mislead people from rural areas who have little understanding of the system. “Rural people fall into cheating traps and lose money,” they said.

Other examples of corruption they noted included:

- hospital employees selling medicines outside the hospital.
- blood being sold.
- poor patients not being allocated beds.
- poor people lying on the floor.

5.4.3 Medical knowledge

Doctors have little understanding about disabilities, agreed the peer researchers.

Doctors have little understanding about disabilities, agreed the peer researchers. One of them told a story about going to a hospital for treatment. He had a high fever and was also in a wheelchair. The doctor assumed

he was using the wheelchair because he had a high fever.

The behaviour of the medical staff is bad, the community peer researchers said, and they give incorrect treatment: “They always give paracetamol and a saline drip, whatever is wrong,” one said. They said poor people do not get good service. One of the community peer researchers from Cox’s Bazar related a story about a widow who went to hospital with a stomach ache:



©Tim McDonnell/Sightsavers

“This widow hadn’t eaten properly for 28 days because of her grief, but the doctor [at the hospital] mistreated her, insulted her verbally and didn’t understand what was wrong with her. Because doctors think they’ll never lose their job, the hospital staff aren’t good.”

Nazma Akter Rasheda, Cox’s Bazar, community peer researcher



There are many ways in which the health system can be improved to make it easier for people who have a disability.

Another community peer researcher from Cox’s Bazar, Mohammad Fazlul Haque, recalled having a motorcycle accident and injuring his leg. He went to the hospital. However, because he said, the doctors get illegal commission to prescribe certain medicines the

doctor examined him and over-treated him while he was asleep. The doctor gave him a very large bill and he had to pay. He never knew whether or not he had needed the medicine.

5.4.4 Alternative medicine

The cost of medical treatment and medicines means that people try traditional medicine instead of taking persons with disabilities to hospital. The father of a man with a physical impairment told a community peer researcher:

“We’ve tried a lot [for my son], but Allah didn’t make it so he could walk. We gave him medicine. People told us to make a hole in the ground for him to kneel in, but it didn’t work. We tied bamboo to his leg, but we couldn’t make him better. We didn’t continue with more treatment because of a lack of money.”

Father of 22-year-old Khan, Cox’s Bazar



5.4.5 What should be done?

Promote inclusive health care

There are many ways in which the health system can be improved to make it easier for people who have a disability and older people to receive the care they need. Doctors should be given training so that they know how to behave with people who have a disability and older people. Community level health care workers also need training so they can give proper treatment.

People with disabilities and older people need to have greater access to healthcare services. To help with this people with disabilities and older people should be given priority in hospitals. Hospitals should also provide separate and special facilities to support people with disabilities, for example the use of Braille.

Tackle access-to-income issues

The cost of medical treatment is an important barrier to healthcare for people with disabilities and older people. Both populations believe that if they have higher incomes, they will be more able to afford medical treatment. People with disabilities and older people need to be supported to increase their income so that they can pay for medical treatment.

The government provides some support, but the administrators are not giving the poor what they are entitled to because of corruption. Those with more influence, for example, younger people or people who support the party in power, receive treatment before people with disabilities or older people. Separate queues would help people with disabilities and older people to be treated first.

5.5 Family support

5.5.1 Older people lacking family support

For older people, the problem of family members moving away or not taking care of them is pervasive, said the community peer researchers. Families think older people are a burden. As they are not earning, they cannot contribute to the family income. Older people explained they have dreams for their children to be educated, but when the children leave to get married they are left alone. The son's wife may ask her husband to leave his parents to save money. An older man told a community peer researcher:

“Our sons have separated from us. It is just the two of us – husband and wife – living here. We’re passing through life with many troubles ... Our two sons live with their wives ... I sell wood here and there, but then I have to beg from my sons.”

Akash, 95 years old, Cox’s Bazar

Another older man said:

“My problem is that since I was about 60 I’ve at times found it impossible to eat, and at other times I don’t eat. Sometimes my sons give me a lot, sometimes they don’t.”

Kamrul, aged 78, Cox’s Bazar

The problem is worse if you do not have sons, the community peer researchers said, as traditionally men stay with their family when they get married and women move to their in-laws. An older woman told them:

“Why will my daughters help? I’ve married them off ... They themselves can barely manage, how will they look after me? They’re not well off at all.”

Mamun, aged 65, Bhashantek



©Tim McDonnell/Sightsavers

Another said:

“I don’t have any sons. I have four daughters. They are all married ... They’re busy with their own families. I don’t have any sons, and my daughters don’t look after me anymore.”

Nipa, aged 70, Bhashantek

The community peer researchers said that if people have no sons they seek a good, honest husband for their daughter so the husband will be like a son and look after them. They will try to convince a daughter's husband to continue to support them. Generally, daughters are more caring towards their parents than their sons, the peer researchers explained, but sometimes a husband is not supportive and a daughter has to stop providing for her parents. This can lead to marriages breaking up, they added.

A widow with only daughters might go and live with a daughter, the community peer researchers said. If the family has property, it will go to the husband so there is an incentive to do this, they said.

Older people are often ashamed of the circumstances they find themselves in. An older woman shared her story:

“I am facing many troubles ... I have six daughters, all of whom got married. My only son also got married but is now separated from me ...

I don't have any money, I can't get food and I can't get medical treatment, due to lack of money. I was without food this morning, so I went to my daughter's house and she gave me one roti [bread] and a cup of tea. Since then I haven't eaten, but I can't tell anyone because I'm shy. If my daughters give me food, I eat. Otherwise I go without food ... My son doesn't take care of me. That is the saddest thing for me. He doesn't even ask me how I am if I meet him in the road. Despite having a son, I have to beg from others. Many people think that because I have a son I don't need help. So I don't get help from the chairman or members of the village. They help others, but they don't help me ... I feel shame to [ask my daughters for help], that's why I don't go to them easily.

Saba, aged 70, Cox's Bazar

The NGO peer researchers heard similar stories of older people being abandoned in old age. Sometimes older people are sent to a city centre to beg, they said. Sometimes they ask to be put there



by the community and are left at bus stations, finding food in nearby shops. They stay there indefinitely.

In some rural areas, people might give a small corner of their garden – a space with a small hut – to an older woman and let her live there. Sometimes they give her a small amount of food, or provide her with *zakat* (religious money) instead of giving it to others. This practice of supporting neighbours persists in rural areas.

But many older people get no support, the NGO peer researchers explained, and they can die as a result, although this is rare in a rural setting. Nasima Khatun, an NGO peer researcher, heard the story of a 75-year-old man:

“This man lives in Malita village of Polash, Charsindhu Union. He was a freedom fighter. He has four daughters and two sons. He kept his children for a long time by doing business. His daughters were married into a good family. The daughters were solvent also. However he can't earn as he did before as he's suffering from illness. His wife no longer does her duties as she was supposed to do before. She eats with her sons and he eats by cooking his own food. He receives the freedom fighter allowance every three months. His wife and sons take this allowance forcefully when he brings it home. Afterwards they don't even care for him. In fact, he is tormented by his sons.

He complained about this matter to the commander and the chairman of Charsindhu. But his wife and children don't listen to anyone. If we go to them, they say they don't do anything like that. They avoid us. Afterwards they torment him. I collected some information and found that it's true that his family members can't tolerate him because he can't earn as he used to earn before.

Nasima Khatun, NGO peer researcher



©Peter Caton/Sightsavers

Nasima heard another story:

“Old people who aren’t capable of working are seen as a burden on the family. Some men and their wives say that it is better to have a debt of 10,000 taka rather than an old person in the family. This problem can only be solved if old people start to earn.”

Nasima Khatun, NGO peer researcher

5.5.2 Persons with disabilities lacking support

Families and community often fail to support persons with disabilities, said the peer researchers. They pay little attention to them and their needs and do not show any signs of respect. A woman with a physical impairment told a peer researcher:

“My family doesn’t respect me. They don’t hear me. If I say anything, they call me a bad name. Apart from my daughter, nobody respects my voice. Nobody cares for me. My husband neglects me greatly. He doesn’t provide me with sufficient food, medicine, betel leaf and nut. He always scolds me.”

Priya, aged 55, Cox’s Bazar

A woman with a visual impairment explained:

“I can’t [attend functions]. If I ask my nephew or niece to take me, they go without me. I can’t move alone ... Who will take me to functions? My parents and siblings have died. I can’t wash my clothes properly, I can’t wash my blankets. I need help to be able to do this work ... There are some people who want to help me, but I can’t visit them on my own. That’s why I often can’t eat. When I go outside, sometimes people give me 10 or 50 taka to buy something to eat, but as I’m visually impaired no one wants to go market with me.”

Laboni, aged 55, Cox’s Bazar

5.5.3 What should be done?

Promote self-esteem

We need to educate people with disabilities and older people so they understand that they are not guilty. It is not their fault. They did not choose to become disabled or get old. They have a right to a life like others. They should realise they are part of the family.

Support independent livelihoods

We are not happy to be seen as a burden to others, we want to establish ourselves and become independent. Family members and neighbours have to be supportive and they need to create employment opportunities for people with disabilities and older people. We can then be financially independent. For older people who do not have anyone in their family, shelter within the community is needed – homes managed by the community.

5.6 Exclusion and mistreatment

5.6.1 Exclusion and mistreatment of persons with disabilities by family members

Mistreatment is an issue affecting many persons with disabilities, according to the stories heard by the community peer researchers. A woman with a visual impairment told a peer researcher:

“I have four children, two sons and two daughters. My elder son died at an early age and my elder daughter got married but she doesn’t live with us. My son-in-law is very rude to me. He behaves very badly towards me as I am blind and poor. He’s never respected me as a mother-in-law. Rather, he calls me ‘kaani’ [a slang term for a blind or visually impaired girl or woman] and uses slang ... He knew about my condition before getting married to my daughter but now he doesn’t care. He doesn’t like me because I’m blind and

I beg for money. He says he didn't get married with a kaani's daughter ...

Society doesn't accept me. I'm neglected by everyone. No one wants to mix with me. People don't behave well towards me. They use slang and scold me for mistakes I haven't made. For example, take the common washroom. If someone leaves it dirty after using it, people will blame me because I'm blind and the chances are I've left it that way, which I didn't. Besides, they call me a symbol of misfortune ...

My husband has never recognised my contribution and help in his life. Rather, he's always regretted marrying me. My brother and sister have helped me several times by giving monetary support, but my husband was never thankful for that. He always blames me and regrets his marriage to me. He complains that he got nothing from me, I could not do anything for him. He wants me to prepare his food whenever he wants it, which can even be early 3am in the morning.

Abida, age not known, Bhashantek

5.6.2 Exclusion and mistreatment of persons with disabilities by the community

Life is especially hard for woman with disabilities who cannot go outside and are hidden in the home. Men have more opportunities to bargain and communicate with the outside world, said the community peer researchers.

The NGO peer researchers agreed that persons with disabilities face many challenges every day. They said people's general attitude is, "I am going somewhere. There is a disabled person in front of me and I have to overtake him, so I push him."

Persons with disabilities are constantly teased. People use slang and bad words to describe them.

Persons with disabilities are constantly teased, the community peer researchers said. People use slang and bad words to describe them. Families believe persons with disabilities to be incapable and a burden. They are not seen as human beings: "They don't know that we have hidden creative potential," a community peer researcher said. A girl with a physical impairment told a peer researcher:

"I can't walk much, my legs and back start aching if I walk ... Everybody calls me lengra' [a slang term for someone with a disability]. My parents and brothers and sisters call me lengra ... It hurts me when they call me lengra. I'm lame, so they use this name for me. If I make a mistake, they mock me by using this name. Outsiders also mock me by using this word."

Nipu, aged 15, Cox's Bazar

The mother of a girl with a physical impairment said:

"My daughter can't bathe herself and neither can she comb her hair ... She can't use her hands for anything ... That's why her younger brothers beat her, and even neighbours bully her. People ask, 'Why is your daughter like this?' ... People gossip a lot. They say, 'You won't be able to get your daughter married' and 'You'll always have to look after her at home' ... [They] talk in an ugly manner and make ugly remarks."

Mother of nine-year-old Megh, Cox's Bazar

A young man with a physical impairment explained, in his story, that he felt excluded from participating in activities. He told a peer researcher:

"All my friends can drive a motorcycle, but I can't drive. My friends can play cricket, but I can't ... Then there are obstacles to studying as well, and obstacles to work. This happens to people with disabilities. I can only do some work. I face many problems because of my disability"

... I can't help my parents now I'm grown up and it's pathetic. Only having one hand is a pain for me." ”
Sujan, aged 18, Cox's Bazar

People with speech impairments face particular difficulties as they cannot tell anyone about their mistreatment. The grandmother of a girl with a hearing and speech impairment shared her story:

“In school, the other students make remarks. [My grand-daughter] cries when they hit her, but she can't tell me who the students are that do this. She can't speak of her studies as all her classmates do ... They hit her with stones, but when she returns home she can't say who has laughed at her and taunted her. She just weeps. So we can't go to the school and tell them about it ... People taunt and tease her so much that she can't even go outside.” ”
Grandmother of seven-year-old Sema, Bhashantek

In addition, the peer researchers told how it was common for persons with mental disabilities to be seen as unmanageable or violent and to be tied up within the house. People in the community like to provoke them so the family does not allow them to go out.

5.6.3 Exploitation of persons with disabilities

Persons with disabilities are often taken advantage of, the community peer researchers said. For example, people cheat them. A visually impaired man's story described what happened when he tried to sell hay in Cox's Bazar:

“People cheated me by giving me a false 500 taka note [in the market].” ”
Abir, aged 40, Cox's Bazar

The community peer researchers explained that the 500 taka and 50 taka notes are nearly all the same size and a similar colour, so people cannot feel the difference between them.



©Snigdha Zaman/ADD

Akkas Molla, a community peer researcher from Bhashantek, who has a visual impairment, told how a boy had failed to pay him when he was selling herbal medicine. He had felt something itching on his back and then sensed the boy had left. The boy, Akkas explained, had dropped liquid on him that irritated to distract him and allow the boy run off.

Mohammad Fazlul Haque, a community peer researcher from Cox's Bazar who is 72 years old, talked about a lack of respect for older people:

“People who are rich and have status are respected when they're older, but if you're poor, people don't respect you. It's traditional to respect older people. I think that as the education system has got better people have become less respectful of older people. Some people are well educated and older, but they are poor and their clothes are not smart so people treat them with disrespect.”

One boy treated me like I was illiterate and poor, but when I spoke in English the boy was surprised that I knew English. Because I'm old and don't dress in a sophisticated way,



he assumed I was poor and illiterate. Lots of children get educated and get married and leave their elderly parents. This is a form of negligence too.”

Mohammad Fazlul Haque, Cox’s Bazar, community peer researcher

The NGO peer researchers said the issue of dependency may be a reason people take advantage of persons with disabilities. Persons with disabilities need support from others and this is seen as a weakness. In addition, persons with disabilities and older women are usually not literate, so it is easy to cheat them. Mostly, it is family members and other influential relatives who exploit them, they said.

5.6.4 Exclusion and exploitation of older people

Older people frequently find themselves taken advantage of, according to the stories heard by the peer researchers. Fatematuz Sohra told the NGO peer researchers the story of a 65-year-old man, who receives a government pension, but “it does not remain in his hand and he can’t spend the money the way he wants to”.

A strategic mistake of older people is they fail to keep the ownership of their properties, the peer researchers said. “They distribute it to their children and then they become vulnerable. They think that their children will be kind to them, but that is not what happens.”

The peer researchers also discussed how older women suffer because they have no property rights. A woman needs to depend on a son or others and

so becomes more vulnerable than a man, especially if her husband dies. If she gets ill or sick she does not get proper treatment. When older women can no longer work they are regarded as useless.

The peer researchers said though that a vulnerable man may suffer even more as women can be better at adapting: “Men are the main decision-makers and when old age comes it becomes difficult for them to obey others’ decisions. They become like an isolated island. Ego issues are stronger for men than for women.”

“One older person is a widower. He leaves the house to take his breakfast and lunch. He thinks his children aren’t happy with him. His wife could have helped with household work, but he can’t, so he thinks he’s a burden on the family.”

Peer researchers’ group discussion

In most cases, sons are the cause when older men suffer, said the NGO peer researchers. Income is a big issue, and as the older man does not have any income the son considers him a burden. In some cases, older men without wives are vulnerable because they cannot communicate with other members in the family.

An older woman without a husband is also vulnerable though:

“We have more widowed older women than men. Women live longer and it is common for a woman to marry an older man. If the woman dies, an older man has options to get married again, but an older woman does not have that option.”

Peer researchers’ group discussion

The children of a widower want their father to remarry so they no longer have responsibility for him, the peer researchers said. They try to find a girl from a poor family to marry him. The peer researchers added that usually it is older people with many children who suffer most. “They are poor

and have spent all their money. Their children are also poor and they all try to pass on responsibility to their siblings. If there are few children, then it is clear who is responsible.”

Widows face particular exclusion issues, the NGO peer researchers stressed. For example, they are not welcome at weddings. “People think that something bad will happen if they join in. To stop them participating in any kind of events, people treat widows badly.”

5.6.5 What should be done?

Promote disability rights

We need an awareness-raising campaign to make sure everyone knows about the rights and capabilities of persons with disabilities. Families should encourage people with disabilities and older people to participate in different activities. We need to make people aware of the behaviour of people with intellectual disabilities. We need to educate people. NGOs cannot do this alone. This needs support from the media and government. If influential people are educated, it can have a stronger impact.

Promote independent livelihoods

People consider those with disabilities as a burden on their family, but if we can create productive work for them, and ensure an income contribution to the household, then maybe the bad treatment will reduce. Income generation is what is likely to change attitudes. Money talks.

Tackle exploitation

We need to make bank notes in different sizes or print Braille on them. We need community-based groups who are organised against cheating and corruption. Not all powerful people are bad. There are a few good powerful people. Sometimes in rural areas, people listen to professor-type people – those who have an education. Powerful people have stopped corruption with these very vulnerable groups after being spoken to.

5.7 Superstition

5.7.1 Bad spirits

It is widely believed in rural areas that disability is the result of a bad spirit visiting a woman during her pregnancy, said the community peer researchers. The grandmother of a girl with an intellectual impairment said:

“My grand-daughter has had this problem since birth. Everyone says it’s because of bad spirits.”

Grandmother of 13-year-old Abida, Cox’s Bazar

The NGO peer researchers heard similar stories and commented that society tends to look down on families which have children with disabilities. For instance, they heard:

“When I went I saw that it was a village in a very rural area ... I saw the boy had covered himself with a cloth and sat down on his thatched house’s yard ... I went to him and when I sat near him I smelt a bad smell. His condition was very bad. It seemed like he was near death. He couldn’t understand anything, couldn’t hear anyone and if someone touched him he felt pain and shouted. His face was terrible. He was becoming raw-boned and in a moribund state. We roamed around the area of his village home. Many of the villagers said that the house was caught by jinn. No one goes to their house. The villagers think that if they mix with the boy or with his family the jinn will catch their children too.”

Shofiqul Islam, NGO story

This latter story had a happy ending, “as ADD was able to show the village that this was superstition. After getting a wheelchair, the boy was able to open a shop which completely changed how he was perceived in the village.”



Superstitions do not just apply to persons with disabilities. They also affect the wider family. One story told to a peer researcher described a 22-year-old woman with disabilities, who lost her sight as a result of poor treatment. The story told how “her younger sister cannot be married for her disability” because “people think that the disability of her elder sister will come and develop in their family” (Masum Khalifa, NGO, story).

5.7.2 ‘Sin’ and ‘bad behaviour’

Other beliefs associate disability with bad behaviour, said the community peer researchers. For example, if a child is born with a disability, the parents may have sinned or cheated others; or if a child has an intellectual impairment or develops a behavioural problem, a spirit may have visited them or a bad person may have touched them. If an older person becomes sick suddenly, one belief has it that the illness is a punishment from Allah as a result of the individual having done something bad in their adolescence.

The NGO peer researchers added that people believe they will have a bad day if they see a child with disabilities in the morning. In addition, parents of children who do not have disabilities do not want their children to mix with children with disabilities because they believe their children will become disabled too. Education levels are low, so people have these beliefs and superstitions, they said.

The NGO peer researchers were told the story of a woman with a physical disability who managed to get married, but was tormented by her in-laws. She was then divorced and it was “thought that this was a result of her unknown sin”.

In rural areas it is believed that older people with cataract have sinned with their eyes – “the blooming of flowers in their eyes”. The NGO peer researchers heard about a man who had cataracts and went to the local religious person – an *houjur* (a traditional village healer). The *houjur* gave the man a piece of stone and told him to scratch his eye twice a day, before dawn. After several days of doing this the cataract became infected and the man was severely injured. He was taken to a Sightsavers centre where a doctor asked him why his eyes were like that. After some time, the man told the whole story.

5.7.3 Other myths

The NGO peer researchers were told the story of a child born with a cleft lip. The parents tried to take the child to the doctor, but other family members refused to let the boy go because the cleft lip was considered to be Allah’s good wishes on the family. If the parents tried to correct the lip, then Allah would be unhappy.

Other myths the peer researchers were told included:

- “If you are disabled you will have a disabled child.”
- “Bad luck will come to you if you marry a person with disabilities.”
- “My day depends on whose face I see first. If it is a person with disabilities or a widow then the whole day will be bad or my work will not be done successfully.”
- “Persons with disabilities cannot learn or work.”
- “Young girls and boys get hysteria as a result of *jinn*.”

5.7.4 What should be done?

Run disability-awareness campaigns

There should be a media campaign about disability and the true causes of it. We need to give the right message and information that people with disabilities and older people are also part of society and have the same rights. We also need to educate people to understand that people with disabilities can contribute.

We could draw murals about disability in poor communities. We could organise a meeting with community elites and religious people to discuss the causes of disability. We could educate teachers in madrasas and schools to teach about the reality of disability.

It would be important to involve the media, to get them to show us positively. District and sub-district level officers could distribute information about this and in meetings raise awareness. There should be posters and banners in busy places and in education centres with positive messages, and we should use the TV to promote positive attitudes.

We need to demonstrate that people with disabilities can work. We need to put evidence in front of people's eyes. Technology is now widespread and we can use it to disseminate messages. People are more likely to believe something if it comes through an electronic device rather than a person.

Improve maternal health

We need to ensure treatment for pregnant mothers to reduce the number of children born with disabilities. We need to ensure the proper medicine and care for pregnant mothers.

5.8 Access to services

5.8.1 Specific services for older people

The health system focuses on maternal health, said the peer researchers. This means that older people do not get their needs met. Reproductive health

Provision is needed for home care, but health professionals are not trained for this.

care ends after childcare, but the health effects of child bearing continue into old age. Many older women suffer from fistula or from prolapse, but only limited services are available.

Mobility problems also mean older people find it hard to get to health centres. They need support to get there, but none is available. There are hospitals in Cox's Bazar, but it costs 50 taka to go to the hospital in a rickshaw, the community peer researchers said.

The NGO peer researchers added that older people get bad treatment or are harassed in the health services. Older people then feel depressed and do not want to go back. Lots of older people do not want to be a burden on society, they said. Some feel that they are going to die soon anyway. There is a fear of annoying sons or daughters if they raise their health problems, and that if they do they may be insulted.

The peer researchers said that older people need care more than cure. Provision is needed for home care, but health professionals are not trained for this. Gerontology is being introduced into the health care curriculum but only very slowly.



©Manna Rahman/HelpAge International



5.8.2 Health services

There are two kinds of health system, said the NGO peer researchers: private and governmental. The private initiatives are expensive but offer better health care than government services. Doctors do not stay in most government hospitals or in rural areas as they prefer to work in private clinics and in Dhaka. Government hospital doctors go to government hospitals in the morning for two to three hours, then they go to their private clinics in the afternoon and evening.

People do not rely on government services, the peer researchers said. However, private health complexes are a long way from villages and widespread corruption exists in them. For example, the complexes receive medicines to distribute free to patients, but instead they are sold to pharmacies. Also, regardless of a patient's health problems, they will be given tests at a diagnostics centre which pays commission for referrals. People get frustrated as they see their money going to these people, they explained.

In addition, they said, doctors do not want to live in rural areas so rural people depend on traditional healers and on pharmacists.

5.8.3 Lack of services for people with mental illnesses

There are no services for persons with mental illnesses in rural areas. People think that mental illness is incurable and they go to traditional healers: "They go to the traditional healer who cannot treat the issues."

The Bangladesh NGO peer researchers heard about a girl whose father died and who gave birth to a child before becoming mentally ill:

“The [mentally ill] girl’s family took her to a traditional healer who said that her vein was broken and started a treatment which wasn’t a proper treatment. After three or four years the family realised this wasn’t right and they took her to the district hospital. After the treatment she started to improve. But the family didn’t continue treatment. It wasn’t possible for them to continue going to the district level so they gave up. This happens in rural areas.”

NGO peer researchers’ group discussion

5.8.4 Insufficient services for people with intellectual impairments

There are some private special schools for autistic children some of which are government schools, but they are limited, said the NGO peer researchers. Some persons with intellectual impairments receive a disability allowance, but they do not receive treatment, they said.

“Poor people don’t know about services for autistic children. Awareness days happen [for autism] but there are no services. The daughter of our Prime Minister promotes autism, but other organisations aren’t working on these issues. It’s not reaching the community level.”

NGO peer researchers’ group discussion

5.8.5 Infrastructure

The community and NGO peer researchers agreed there is a lack of specially-adapted infrastructure and facilities in hospitals, schools, transport and recreational activities etc. It is difficult to get to these facilities, and in particular hospitals are not accessible, because of no ramps.

Education institutions are the same, they said. There is not enough special equipment for persons with disabilities. School children who have a disability are not allowed to school events and sports because the teachers do not let them. They assume they will not be able to play or join in and events are not adapted for persons with disabilities. However, there is one organisation – the Society for the Welfare of the Intellectually Disabled, that provides some assessment, relief services and training.

5.8.6 What should be done?

Make public services fully accessible

There should be a separate counter in hospitals for people with disabilities. Transport should be accessible. All public offices should be accessible. We need appropriate legal support for people with disabilities and older people. Local government officials must respect people with disabilities and they need to arrange adapted services or accessible facilities for them.

Make sporting and cultural events accessible

We should arrange cultural events for people with disabilities and older people. There are 10 blind cricket clubs at the district level, but they are not allowed to play in stadiums. They should be allowed to. Marriage events in community centres need to become accessible, so everyone can attend.

5.9 Mobility

5.9.1 Mobility and physical disabilities

Persons with disabilities have mobility problems

and wheelchairs are expensive, with the spare parts unavailable, said the peer researchers. The government cannot provide enough special equipment, which often has to be imported.

The peer researchers also highlighted difficulties in accessing toilet facilities. A man with a physical impairment told them:

“I can’t even get up from bed [due to paralysis] and I have to urinate and pass faeces in bed. I eat twice a day, but I can’t eat a third time. There’s no money.”

Amit, aged 30, Cox’s Bazar

Another man with a physical impairment said:

“I go to the toilet by crawling ... I wish I could have a latrine. I feel ashamed because I have to go to the bathroom in the open.”

Khan, aged 22, Cox’s Bazar

Public transport is a problem for persons with disabilities and older people, the community peer researchers stressed. In Cox’s Bazar, they explained, there are stairs to climb to get on a bus. Also, buses do not stop completely, making it dangerous to get on and off. There are nine seats for women, children and persons with disabilities on every bus, but older people do not have allocated seats.

Flyover bridges, which are inaccessible to persons unable to use stairs, make crossing roads dangerous for persons with disabilities and older people.

5.9.2 Mobility and people who are blind or have low vision

A man with a visual impairment told a community peer researcher:

“I face mobility problems. I can’t work independently ... I can’t move alone, I can only move with other people’s help.”

Abir, aged 40, Cox’s Bazar

An older man with a visual impairment told another:

“I can’t move on the road and market. I can’t cross the road. I don’t understand the location and movement of cars.”

Dewan, aged 66, Bhashantek

The community peer researchers said that some people who are blind or have low vision use white canes or have sighted guides because they are involved in self-help groups. Those outside of these groups are less likely to use canes or guides because they can lead to bullying and embarrassment. So in the Cox’s Bazar self-help group, they want floor-level sticks, which are more expensive. The quality of government-issued white canes is often bad and they often break, they added.

5.9.3 Mobility and people with hearing and speech impairments

People with hearing and speech impairments cannot communicate with drivers or rickshaw pullers to say where they want to go. Often they cannot hear car horns and they can be knocked down by cars, said the peer researchers.

5.9.4 What should be done?

Make public transport fully accessible

There should be greater awareness of how to make buses and roads more accessible. For example, the public needs to be aware that they should help people with disabilities and older people. The traffic police and transport and infrastructure departments should be made aware of the needs of people with disabilities when planning and building. NGOs should advocate for this. Older people with disabilities should have priority when getting on buses and have allocated seats.

Provide specialist equipment

Other organisations should provide white canes, not just groups that work with people who are blind or have low vision.

5.10 Marriage

5.10.1 Marriage and women with disabilities

Women are not valued as much as men in Bangladesh society, and are marginalised as a result.

Women are not valued as much as men in Bangladesh society, and are marginalised as a result, the peer researchers agreed. Bangladesh is a male-dominated society and women’s opinions are ignored, so they have low

confidence. Women are seen as a burden. While sons can provide financial support, daughters leave their family when they get married. Also, dowries must be paid for daughters, and if a girl has a disability the dowry is higher than if she has not. The peer researchers explained that because of these attitudes women with disabilities are often hidden away in their homes, their challenges unknown to the rest of the community.

Both men with or without disabilities are not interested in marrying women with disabilities, the peer researchers said. It is seen as shameful and they will face criticism. However, men with disabilities do sometimes marry women without disabilities.

In general, people believe that women with disabilities cannot manage household activities such as cooking and cleaning. Also, they believe that if a mother has a disability, her children will be affected too – especially the parents of boys.

A woman with a visual impairment told a community peer researcher:

“I couldn’t marry, I couldn’t enjoy my life and I couldn’t have a family.”

Laboni, aged 55, Cox’s Bazar

The NGO peer researchers also found that for women with severe physical disabilities, especially if they use a wheelchair, it is difficult to get married. This is also true of women with intellectual impairments.

It is easier for persons with disabilities in low-income groups to get married than those from rich families because prestige issues must also be considered with the latter group.

5.10.2 Mistreatment of women with disabilities

If a woman with a physical disability does get married, it is common for her to be taken advantage of and for her husband to treat her badly, the peer researchers said. They explained that a man without disabilities mostly marries a woman with disabilities to access her family land – and they leave her once they have the resource. Sometimes, the parents arrange the marriage of children with disabilities too quickly and choose an inappropriate spouse. A woman with a physical impairment told a community peer researcher:

“[My husband] is my cousin. His father and elder brother took me, but my mother didn’t want to give me away. My father died when I was young. They took me by force, despite my mother’s refusal. Then all of our lands were divided, so we didn’t have anywhere to live. So we came to Dhaka to make a living. My husband used to pull a rickshaw, but one day he went to work and went missing.”

Nishat, aged 55, Bhashantek

It is common for husbands to leave if their wife becomes physically disabled. A woman with a physical disability gave her story:

“The members of my family don’t feel that I’ve any worth at all. They don’t listen to me and if I say anything at all they’re extremely abusive. Except for my daughter, nobody gives any importance at all to what

I say or looks after me. My husband is even more irritated. He doesn’t make sure that I’m properly fed or give me medication. Neither does he give me betel nuts to chew on or mouth fresheners. All the time he abuses me. There is nothing for me to do except maintain a painful silence ... [My husband does earn], but he doesn’t look after me – he’s with his younger wife. I carry on with great difficulty.

“I’m worried about the future. Once my daughter is married, who will look after me? If my son has work I can carry on, but if he doesn’t earn I have to approach my relatives. However, how much can my relatives look after me? For me, a day seems like a year. With great sorrow I sit alone and weep. He married me before I was disabled.”

Tamanna, aged 55, Cox’s Bazar

The poorest people, beggars in particular, sometimes marry women with disabilities to get shelter, and then they move on and marry again, the peer researchers said. These people have multiple wives.

The NGO peer researchers said that if a man marries a woman with disabilities, sometimes the family of the man can be reluctant to accept the couple and, after two or three years, the man will divorce his wife. Even when emotions are involved



©Snigdha Zaman/ADD

at first, a man can end up losing his patience and affection for his wife when he has to mix with society. Sometimes a wife goes back to her parents because of an intolerable level of torment, the peer researchers added.

Occasionally there were more positive stories. The NGO peer researchers were told the story of one boy educated to secondary school level (year 10 or 11):

“There was a conversation between this boy’s family and the family of a girl with disabilities, but the parents of the boy were abusive towards the girl. Somehow this boy was very educated and he was aware of disability issues. On the spot he declared that he would marry this girl. He brought the bride home on his shoulders and married her and they had a happy family and two children without any kind of disabilities. He told his parents, ‘See – nothing happened to me.’”

NGO story

5.10.3 What should be done?

Educate and train women with disabilities

Women with disabilities should be educated and given vocational skills and training to empower them. They can be skilled and it will help them to bargain with their husband’s family, as well as help them get a job. Job opportunities should be created in the government sector. If we can be financially independent, we will be valued by the community and we are more likely to marry.

Promote positive images of women with disabilities

The problem is that all men (with and without disabilities) do not want to marry women with disabilities, but women need to get married because they are dependent on their husbands. Even we, the male peer researchers ourselves, do not want to marry a woman with disabilities. Through the media, we need to

promote the fact that women with disabilities are capable and are human too. Some educated girls with disabilities cannot get married, so the government should encourage non-disabled men to marry women with disabilities.

5.11 Land

5.11.1 Slum living

In Bhashantek, nobody has their own land; people live on government land.

In Bhashantek, nobody has their own land; people live on government land, the community peer researchers explained. This may be the result of people losing their land in their village

because of flood erosion. In the slum, they added, people live precarious existences, hand to mouth, and have no money to purchase land or a home. An older woman told a community peer researcher:

“People are taking away the government area. Now I’m worried about where I’ll live in the near future.”

Sadia, aged about 80, Bhashantek

An older man with a visual impairment said:

“I’m living like a nest-less bird. I have debt. I have to survive by begging. I live on government land.”

Dewan, aged 66, Bhashantek

The Bhashantek community peer researchers explained that there had been a government project for the rehabilitation of Bhashantek slum, but most people could not afford the security deposit to move into the apartments that were built. The apartments were given to government workers to lease and others were buying them. An older man explained in his story:

“They didn’t even send my name [to be rehabilitated from the slum]... What can I do if my name isn’t included? The chairman and members took everything. If they don’t give, what can I do? I can’t force them and say, ‘include me’... The forms are given to those who have money, 60,000-70,000 taka, I have heard. But we weren’t informed.”

Mamud, aged 65, Bhashantek

The community peer researchers said that people thought that rehabilitation meant the apartments would be free or they would only pay out once, but people have to pay rent. They have to pay 250,000 taka over 10 years. “It is not possible for poor persons with disabilities and older people to afford this.” Another older man told them:

“It’s very hard to lead life without money. We face many troubles ... Sometimes we starve. The government is going to break up this slum area, then where will we stay?... We don’t get [rehabilitated land] for free. At first we’d need to pay 10,000 taka and then 45,000 taka later. After that, 300,000 taka needs to be paid a month ... The outsiders took 400 [plots of land] ... They have money and they took it. The people in the slum only got 218 plots ... Who’s there to hear our words? The members and the chairmen tell us to pay money otherwise they won’t put our names forward.”

Rana, aged 65, Bhashantek

An older woman in Bhashantek said:

“Now, where Allah takes me ... I can’t pay 10,000 taka to fill the form [to be rehabilitated]. I wasn’t able to do that. Also if I get this I have to pay more money to move in. I can’t manage [to buy] food for eating.”

Tasin, aged 70, Bhashantek

5.11.2 Land inheritance

Persons with disabilities generally do not inherit land and homes, instead it goes to their siblings, said the peer researchers. Families do not know the law. As they believe a person with a disability cannot work or get married, they question why they should inherit land.

The peer researchers explained that people with intellectual impairments are not allowed to own land legally, and women cannot inherit land at all. Sons inherit land, so a widow does not inherit. Sometimes, widows are given a small percentage, but poor families tend not to give their mothers anything. Widows have to live with their sons. If a woman does not get married, she has to depend on her brothers.

5.11.3 What should be done?

Provide government land

Powerful people reserve government lands and property, so we need to make land more freely available. NGOs and the government should provide subsidised land for people with disabilities and older people, and we could pay in instalments. There was a rehabilitation project for another slum and the instalments [for apartments] were much cheaper and they included vegetable gardens. The NGOs need to lobby the government to provide land for older people and people with disabilities.

Rehabilitate beggars and provide sheltered care

There are rehabilitation programmes for beggars, but they only give them 300 or 400 taka before sending them home. The government should provide enough resources for rehabilitation programmes. They should also provide sheltered care homes for older people.

5.12 Rape and sexual abuse

5.12.1 Women, disability and vulnerability

Many stories of the rape and sexual harassment of women with disabilities were told to the NGO peer researchers. For example:

“[People] said that she was the result of her parents’ sins. People called her deaf and mute and they neglected her. She cried a lot at times. Because she was disabled and poor, she couldn’t study. Her mother worked in others’ houses and her brothers worked in others’ fields, but it was difficult to get food twice a day. As she was growing up her mother and brothers worried. Generally, in our country, girls are neglected. Moreover, if they are disabled there is no end to their suffering.

At the age of 16 this girl went to a jute field to fetch wood. There, the son of a powerful chairman of the village raped her. She went back to her home, bloodied and in a lot of pain, and after she reached home she collapsed. Her brother’s wife asked her what had happened and the girl told her using sign language. Later, she died. The girl’s elder brother wanted to file a case against the chairman’s son, but the chairman’s people threatened him. He did file the case, but the police didn’t take it on because the chairman was powerful. The police said that [the girl’s death] was suicide so they couldn’t take on the case. They threatened the girl’s elder brother and made him sign that it was suicide.... Still, today, there has been no justice.”

Syumon Hossain Bijoy, NGO story

5.12.2 Particular vulnerabilities

Persons with visual, speech or intellectual impairments, as well as children, are the most vulnerable to rape and sexual harassment, said the peer researchers. It is easy to exploit and abuse these adults and children because:

They do not share experiences easily and many cannot communicate.

- Girls with disabilities may live alone and it is not possible to ensure that they are accompanied full time.
- Chocolates and ice cream are often used to draw in those with intellectual impairments.

The NGO peer researchers were told the story of a woman with an intellectual impairment who became pregnant and had a child every year, but she could not say who the man was who made her pregnant.

They were also told the story of a girl with hearing and speech impairments who would be left alone when her mother went to work. Her uncle often used to come to the house and one day he raped her. When the mother came back from work that day the girl was crying but she could not say why. The mother took the girl to hospital where doctors understood what had happened. The girl later made her mother understand that the person who raped her was the uncle. However, powerful people threatened the girl, that if she complained further the uncle would divorce her aunt and the aunt would then become helpless. Rape happens within houses and is often committed by the family members of victims, the peer researchers said.

Technology is providing new opportunities for abuse, they added. Most mobile phones have cameras and when people commit sex crimes they take pictures and threaten the victim, saying that if the victim says anything about the crime they will publish the pictures on the internet. The NGO peer researchers said that everybody has a mobile phone and technologies are misleading the younger generation: “Pornography has become very easy to access. You easily go to the cyber café. You can browse and see all of this pornography and incite these crimes.”

The law is not strong enough, the NGO peer researchers agreed. Providing evidence of rape is sometimes difficult, and in most cases, the abusers are powerful and influential. Samira Khatun, an NGO peer researcher, said that several women with hearing impairments tried to gain justice in various



rape cases, but court lawyers did not understand sign language. However if a girl tries to explain who a perpetrator was, it is not acceptable in court. Even medical reports are difficult to use because these need to be completed within six hours [of the offence to be used in court]. Samira said the law for rape victims is inadequate. Furthermore, in court lawyers are harsh towards women who have been raped: “The words that they use are a kind of another rape. The girls feel so embarrassed that they don’t want to go there.”

5.12.3 Power, rape and sexual abuse

Rapes are often committed by people with power, said the NGO peer researchers. One story they were told was as follows:

“**[A woman] took a job in a paint washing factory. After doing the job for a few days the factory manager raped her. She was very scared after the rape. That’s why she didn’t inform her family and went to bed**

without saying anything that day. She didn’t want to work for two days. When her mum forced her to go to work, she told her in sign language that the factory manager had raped her. However, the [factory] owner took the side of the manager and threatened her.

Mahua Akhtar Dipa, NGO story

The whole family was forced to move – a common outcome after rape.

As a result of the incident in this story, the whole family was forced to move – a common outcome after rape. The NGO peer researchers were also told about a girl with disabilities who was brutally

raped by a 60-year-old man. The man was caught by local people and put in jail. The girl was sent to a hospital where she was examined before being sent back to her quiet village. At first, village people stood by the girl, but after a few days the situation changed as the rapist was a local influential and powerful person. The medical report was altered in exchange for money. After the police report came down on the side of the rapist, the man came out of jail and pressured the victim’s family into leaving the area. In this case, the peer researchers said, the only thing the NGO that was involved in the case could do was to provide the girl with counselling “so she didn’t become mentally devastated”.

Sometimes, locally-arranged settlements see abusers giving money to the families of victims. The victims rarely benefit, however. The following story was told to an NGO peer researcher:

“**She was a speech and hearing impaired girl who got raped by one of her cousins. After that she became pregnant. The boy denied this incident. When the girl’s family came to know about it they pressurised the boy into marriage with the girl. The cousin’s brother resolved the matter with his family and local respectable people by giving**

some money to the girl's father. The girl's father took the money because he was greedy and also a drug addict. But still the girl was pregnant.” ”

Shofiqul Islam, NGO story

Sometimes victims are married to abusers, whether the girl wants it or not.

“We say we don't know who's doing this. But it's not true. We know. It's a kind of social stigma. If you know that one of my children is raped, there's a natural tendency to hide that. It's shameful in this society, so we tend to hide it.” ”

Nasima Khatun, NGO peer researcher

5.12.4 Views of the community peer researchers

The community peer researchers did not collect any stories about rape or sexual harassment. As the NGO peer researchers heard so many such tales, there was a workshop discussion about why this might have been and whether or not the community peer researchers thought this was an important issue.



©Zul Mukhida/Sightsavers

The response from Bhashantek

It was agreed that women with disabilities are more vulnerable to sexual abuse and rape. One community peer researcher explained that girls who work as domestic helpers (not necessarily girls with disabilities) are also vulnerable to abuse. It happens often, he said, but it is not known about because people are ashamed to speak

Every day in the newspapers there are reports of rape.

about it. Every day in the newspapers there are reports of rape. These women can report the rapes, but because many women with speech and hearing impairments, or with intellectual impairments, cannot share or explain their experiences, they do not get reported. A second peer researcher said there is a social division between rich and poor. It is harder to get richer people to admit that abuse happens to their daughters because of the social stigma involved.

It was explained that abuse is widespread but not spoken about. Women do not only suffer from rape and sexual abuse. They also suffer from physical abuse. One woman in a wheelchair [apparently] committed suicide by hanging herself. Nobody believed it. Murder was suspected but no one was ever prosecuted. In a district close to Dhaka, a newspaper reported that a group of people murdered a woman with an intellectual impairment because they thought she was a kidnapper so she was beaten to death.

The response from Cox's Bazar

The community peer researchers said abuse happens in poor families: “It is common. It gets solved through the village justice committee. We make the man pay compensation or we make the man marry the girl.” One peer researcher believed that there are 34 disability self-help groups in the Cox's Bazar area and there were examples of abuse within these, so he thought it is very common:



“When the girls try to report rape, corrupt police and lawyers abuse and rape that girl again. Three girls with intellectual impairments were raped by a business man, a police man and an anonymous man. They got pregnant and the newspaper published this, but they never got justice. How can they get justice when one was a policeman?”

Yet another said that women with disabilities are more vulnerable:

“One girl with hearing and speech impairments was raped by her cousin and became pregnant. The boy’s family told the girl not to tell her family and they made her abort the child. But the family found out because the neighbour spoke to her in sign language and then they knew. The families solved the issue between themselves. They didn’t involve the law.”

It was agreed that women with disabilities are more likely to be victims:

“A girl with a physical impairment was in a self-help group and she worked in a doctor’s surgery. She had a relationship with her colleague and she got married, but the family of the husband didn’t accept the marriage and when she became pregnant the in-laws wanted her to abort the pregnancy. She tried to set fire to herself and threw herself into the river. Later, she died. We think it’s very common – not just for disabled girls, but for others too.”

5.12.5 What should be done?

Mobilise against rape

Village justice committees should educate families. They should convey messages to all families in the community. There should be public punishment for the perpetrators to discourage people, to show that they cannot escape justice. Most people are religious, so we should stress that religious values go against rape.

Strengthen the justice system

We also need a stronger legal system. At the moment, you have to prosecute within a year and influential people make cases drag on so time runs out to take action. We need organisations to protect witnesses and victims. There should be a committee in each community on violence against women. This should be responsible for preventing and reporting these crimes (at the union or sub-district level). The mediation courts at community level have limitations. They cannot deal with all disputes. They can only dissolve local land disputes and small crimes like theft. Rape cases cannot be taken to them. We need to educate local government officials. The criminal courts will ask them about rapes, so they need to understand the crime better.



5.13 The role of grassroots community-based organisations

5.13.1 Supporting the wrong kinds of activities

The NGO peer researchers heard several stories about the role of NGOs and community-based

organisations supporting persons with disabilities and older people. They said that often NGOs support the wrong income-generating activities and fail to do a proper needs assessment before giving cash. For example, they provide a goat to anyone who has a disability, but to

They said that often NGOs support the wrong income-generating activities and fail to do a proper needs assessment.

rear a goat a person needs to buy food and they may not have the money for that. “So how can they make money from these kinds of initiatives?” the NGO peer researchers asked.

5.13.2 Lack of accountability

NGOs are not accountable to the communities in which they work, but rather to the donor, said the NGO peer researchers:

“When you get funds from your donor you have to be accountable. You have to provide 10 goats and you have a deadline. You just get the goats out to people. Programmes are based on prescribed formats from the donors. Why is our system like that – is it because of the Millennium Development Goals? Why are other important issues not addressed? Is it because they are chasing goals?”
NGO peer researchers’ group discussion

5.13.3 Do NGOs adopt the right approach?

The NGO peer researchers group discussed how they could make a difference. There were many stories of positive change for individuals that they had heard and many of failure too. But what would make a difference on a big scale in relation to livelihoods, services, attitudes and behaviours?

“Whatever we do, the most important thing is ensuring regular income of any person, because if you don’t have income you’re not well respected in your community and family.”
Md Al Amin, NGO peer researcher

Al Amin said that so far their interventions had been rights-based – advocacy and lobbying:

“But for an older person with disabilities, they say, ‘What will I do with advocacy work? I don’t have food in my stomach. What will I do with quotas? I need food now.’ They’re not happy with

these rights-based activities. The government declared a 10 per cent quota [for access to government jobs]. Rights are important, but they're no use to people until they have food."

Md Al Amin, NGO peer researcher



Lipi Rahman shared the same concern:

"Older people's associations are trying to find new leadership, but it's always the same faces in the community who are active because these people don't have to think about their day-to-day income. People who are really poor don't come to rights-based activities.

We're opportunist. It's easy to get solvent people on committees. We spend a lot of time on seminar and workshop activities, rather than getting to really vulnerable people within communities. We're not willing to make that effort. This is our lack of honesty and willingness and commitment. Women don't have the same flexibility and mobility. An older man doesn't have to ask his sons or daughter-in-law if he can go to a meeting. An older woman does."

Lipi Rahman, NGO peer researcher



The group talked about why NGOs provide support which may not be needed. They said

In some instances, such as a natural disaster, the government will write off a debt when an NGO will not.

disaster, the government will write off a debt when an NGO will not.

NGOs have an interest in providing loans because that is part of their business. Hence, they do not refer people to government banks who would provide loans with less interest. However, in some instances, such as a natural

5.13.4 Community involvement and sustainability

One story the NGO peer researchers heard went as follows:

"One person, he has three kids, and he pulls rickshaws and is the only one earning. He says, 'I can't struggle anymore. I can buy food for my family or I can buy treatment.' His son says, 'Why don't you die?' His father got upset and he told other older people. They told the Imam. The Imam said [to the son], 'Take care of your father or leave the village.' Then the son became scared and he worked more."

NGO peer researcher



©Snigdha Zaman/ADD

The NGO peer researchers discussed whether the community was more likely to support cases of older people than those of persons with disabilities. It was agreed that they probably would, but “they have not really involved community people with disability issues. They work alone.” Involving the community to ensure initiatives are sustainable is important, however, they agreed:

“Community people should be involved, because if they’re not in favour of initiatives they won’t be sustainable. There were different people with disabilities in the market. Other people in the market didn’t allow them to sit and sell. But the [community people] said, ‘Isn’t it better that he is earning rather than begging?’ Then the [people in the market] allowed those people to sit for their businesses.”

NGO peer group discussion

One NGO peer researcher said that they helped a girl with disabilities for two years but when support was withdrawn, everything stopped. Why? He explained they have made the community dependent on NGOs. “We need to make long-term programmes rather than projects.”



©Snigdha Zaman/ADD

Another said that the fact remained that an organisation started a project with a donation, and after three years it closed. This peer researcher added that they knew an intermediate-level blind teacher who worked for a project at Dhanmondi. This man’s family was very poor and when he got his job he had hopes for a new start. He got married and had a good life for the next four years. But then the project suddenly ended. The lifestyle this man had become used to, like living in a better place and having a better status, ended too. The man’s life became very difficult. He was too old to get a government job and when he tried to get a job at other NGOs they turned him down, saying they could not give him half the salary he used to earn. The peer researcher said that in the end the man started begging in Narayanganj.

Lipi Rahman highlighted similar issues for older people:

“The government is not doing programme-based work. They are doing project-based work. By providing cash grants, do we think that the sufferings of people with disabilities and older people will be met? It will be because some people will get some support. Others are saying it won’t make a difference if it’s for just one or two years.”

Lipi Rahman, NGO peer researcher

Some older people’s committees have been set up, said the NGO peer researchers. For example in some areas older people have been successfully included in disaster preparation committees. Generally, these have involved people who are relatively solvent, not the ultra-poor. But when they can include persons with disabilities and older people on committees then maybe government will develop programmes, said the peer researchers.

5.13.5 The priorities of NGOs

What NGOs can do is tiny compared to what government can do, said the NGO peer researchers:



“We can only act as a pressure group. There is a huge structure. Why are some people not getting support? Why are some people being excluded? This is the limitation of NGOs. We can’t go to every person, but government can.”

Peer researchers’ group discussion

They said that one of the most effective roles that NGOs can play is to set up pilot projects that can later be taken up by government. The NGO peer researchers pointed to the example of the Centre for Disability and Development. A satellite therapeutic service by mobile phone set up was identified by the Ministry of Social Welfare as working well and so the Ministry took it on board.

The NGO peer researchers said it is also important to get people involved at all levels of government. One peer researcher asked about the municipality which had a development committee. She said people needed to be involved at community level and there needed to be beneficiary-level people on the committee:

“Somehow we need to be involved in local-level committees. They can support these vulnerable people to become able to enter the activities of government. Government structures will be there after we are.”

Nasima Khatun, NGO peer researcher

In Samira Khatun’s working areas there are 20 PWD organisations. They campaign and advocate whenever a new committee is formed, she said, and inform the committees that they want to be represented.

The peer researchers discussed why there were not many women on committees. One reason given was that local government representation is not gender sensitive. In committees you cannot find many women participating because they do not mix outside the home. Even the committees do not trust the leadership qualities of women. Nasima Khatun pointed out that there are no proper toilet facilities and women do not feel comfortable travelling to attend committee meetings. Additionally, in areas like Cox’s Bazar and Chittagong, women usually do not come out in front of men and they use veils. If you manage to get some women on committees, they will not contribute. So they attend, but it is tokenism, they said. Women lack experience and skills in articulating.

Young women participate in the forums, but women with disabilities and older women do not come forward.

The peer researchers said that they have many organisations – 60 to 70 – who work for women’s empowerment, and a separate committee. Young women participate in the forums, but women with disabilities and older women do not come forward. Md Al Amin said that ADD is engaged in committees in 27 districts, but there is still a gender representation issue. Al Amin agreed with Nasima:



“When we involve women individually they actively participate, but when they meet with the men’s groups, men take the lead and women do not participate. In front of men, women become less active.”

Md Al Amin, NGO peer researcher

Lipi Rahman talked about the older women involved in 45 groups in three districts. “They are leading and talking, but they never attend when there are common groups with both women and men,” she said.

There are some examples of positive change, the NGO peer group researchers said. For example, Md Fazlul Karim worked in an area with 107 groups, each of which had 25 to 30 women involved. The groups have criteria that older women, persons with disabilities and widows, as well as women who have been abandoned and are living alone, should be represented. At every meeting, the women

themselves select the issue to be discussed. They provide the information and signposting to where people should go if they need things. The chairman works closely with these groups and has made it clear that he will support their ongoing work even when new programmes come along.

5.13.6 Capacity development and zservice delivery

The NGO peer researcher group discussed the importance of capacity building. This was agreed to be important because NGOs can only get services to small numbers of people.

One peer researcher said that if you are in a good position, then capacity building comes first, “because the need is to put pressure on local government to provide services that can get to the mass of people, and which are not getting to the poorest. If you are really poor then food comes first, and shelter and health services. After that, comes education and skill development.” Another added that there is an aspiration to do more capacity building, “but it is not happening very much. We are not doing it.”

5.13.7 Views of the community peer researchers

The role of grassroots organisations was another area that failed to come up in any of the stories that the community peer researchers collected or in their subsequent discussions. Their perspectives on the role of NGOs and community-based organisations was discussed in their workshop.

Hafez Mohammad Jafar Alam, a community peer researcher from Cox’s Bazar, described what happens when NGOs invite visitors to check their programmes:

“They only give us two minutes to speak and they tell us what to say. They give us mobility and orientation training, but real rehabilitation is not happening. The NGOs provide a ‘per diem’ for government officials to come to meetings. Why isn’t it given directly to people with disabilities? The money goes to high officials.

In this workshop, our thinking capacities have been developed, but at the field level there isn't any opportunity to enhance our capacities and discuss things like this. The government should listen to our needs, at different meetings. They need to let us participate and talk and enhance our capacities, and then we can express our needs. There's not enough support. Organisations could be more sincere and organise more capacity-building programmes, involve us in more discussions and planning, and in the implementation process. More money should be spent on capacity building and participation.



**Hafez Mohammad Jafar Alam,
Cox's Bazar, community peer researcher**

Another community peer researcher, argued that training and the creation of more employment opportunities is needed:

“NGOs are not doing enough. Their scope should be increased. And NGOs should be more sympathetic and understand persons with disabilities better – discuss with us and provide more facilities.”



Nazma Akter Rasheda, community peer researcher, Cox's Bazar

Md Kamal Hossain said that NGO projects are too short. They last for one or two years and then the projects end. From ADD, some children received an education and some people were started in small businesses, but this was not sustainable, he explained, adding that NGO projects should plan for benefits to continue when they end. Selina Begum said employment and a place to live is needed. Kamal explained that persons with

NGO projects are too short. They last for one or two years and then the projects end.

disabilities feel that they do not just need money, training or advocacy:

“Land and employment are priorities. If we don't get that, we can't develop. Actually, everything is important – food, shelter, medical treatment, education. We earn 3,000 or 4,000 taka a month. It's not enough. Sometimes we only eat once or twice a day. Ultimately, the most important thing is permanent shelter for the people who live in Bhashantek.”



Md Kamal Hossain, community peer researcher, Bhashantek

A community peer researcher from Cox's Bazar said:

“We got independence 42 years ago, but still normal people didn't get independence. The political parties got independence. Still the general public are suffering. We, poor people with disabilities and older people, don't get government land. Political parties use this land to build on, but poor people can't use this land. We have a quota for female parliamentarians, but there's no quota for people with disabilities, and that's why no progress is made.”



Hafez Mohammad Jafar Alam, community peer researcher, Cox's Bazar



©Snigdha Zaman/ADD



6. Evaluation of the peer research process

The peer researchers were asked to discuss in pairs and answer the following questions about undertaking the research:

- What have you most enjoyed?
- What have you found difficult?
- What did you learn about how to do research?
- How else could you use the research?

The following are some of their responses:

“It was an opportunity to communicate with people with disabilities and older people and share their feelings and learn about their suffering. I enjoyed this. We faced difficulty mainly with people with mental impairments and people who couldn’t communicate. We learned how to collect stories and how to identify the good sides and the bad sides of their lives. We can use this experience in programmes or projects.”

Mohammad Fazlul Haque, community peer researcher, Cox’s Bazar

“We collected information from people who were like us. We went to the same kind of people. We collected sorrows and happinesses. As they were the same kind of people they could share their feelings. There were time limitations. There were lots of other stories to be shared. If we’d more time we’d have got more stories and more information. As we went to rural areas people were mostly illiterate, so it was a struggle to make them understand what we were asking. We collected 17 stories in each group, but more than 100 were possible. As we had no previous training we learned how to go into the community and collect stories.

“With a further opportunity, we could do it more successfully because we’ve learned at least something. I hope we could do much better if we’re given further chances.”

Rozina Akter and Hafez Mohammad Jafar Alam, community peer researchers, Cox’s Bazar

“I enjoyed the whole thing. It was a very new kind of thing. We went to people in the community and collected stories, and they could share and swap stories with us. In the beginning there were difficulties in getting people to understand what we were asking, but in the end it was OK. We learned how to get real-life information from people, and how to collect sadness or sorrows. If there are similar initiatives, we could do the same again.”

Shefali Bala Dey, community peer researcher, Cox’s Bazar

“I hadn’t done this kind of research work. It was a new activity. I enjoyed it. The challenges were in how people in the community reacted. ‘Lots of people come but nothing changes in our life,’ they said. ‘What will you give us.’ I learned how to talk with people and bring out inner stories from them. This might provide opportunities to get other research.”

Selina Begum, community peer researcher, Bhashantek

“I was happy that I could be part of this whole research. My peers enjoyed it which is why I enjoyed it. They showed respect to me, especially when they

got the printed copies [of documentation] in their hand. There were time limitations. We found some peers wanted to share positive stories only. I learned that in doing research many factors have to be considered: how to go to people, and that before taking any kind of decision you need to do research. I also learned about participatory research work which I will try to apply in my organisation.”

Most Samira Khatun, NGO peer researcher



sufferings because they didn't want to highlight the failings of their organisations. So we had to probe again and again and again. We learned how to identify the main issues through telling a story and how to analyse those issues. We had different activities like training. We can use this skill in making priorities in training. It will be easier for us to write reports of projects because we've writing skills [now] and this will help us write project proposals for donors.”

Md Al Amin and A S M Ashiqur Rahman, NGO peer researchers



“In previous research, we were given questions and collected answers. These were not participatory research processes. We very much enjoyed being involved in the whole process. The questions were so good. We learned how to probe. This enhanced our speaking capacity. When we went to speak to older people's leaders it was difficult to bring them out of themselves to talk about personal things. Some appeared to take questions and said 'I will give back to you'. Two didn't want to tell us stories. It was difficult to balance the project we work on and this work, as the project was at an end. Project staff thought that the stories meant that there would be a new project. We learned how to probe, how to do analysis, how to identify issues. We're now more used to writing narratives. It's given us a new angle in thinking about the lives of older people. We've been working for eight years, and hadn't thought in this way before. This research has given us new insights into why things fail.”

Lipi Rahman and Mohammad Fazlul Haque, NGO peer researchers



“We got to know the way things really look by going physically to the slums. We learned about different organisations' activities. We learned more about the issues. Time was limited. Getting time commitment from peers was difficult. Peers didn't want to talk negatively about their organisations. Voice recorders were not easy to use for all of the participants. We learned how to analyse stories, how to collect stories from people, how to use the time, how to document and record the stories, how to speak to people on specific issues and how to convince people [to engage in the research]. Our experience will help us in advocating the rights of people with disabilities and older people. Future development work can use this and it will help us in planning.”

Nasima Khatun and Md Elias Talukder, NGO peer researchers



“We had no previous experience of research. In this research we used voice recorders to ensure authenticity. We wrote down exactly what people said. Many of our peers were hesitant to share their

“We enjoyed the whole process a lot. We built new relationships with different people. We collected information from different people. It was a new methodology of collecting information through a story. We learned about the real lives of people with disabilities and older people. We learned about unknown issues. We enjoyed

the way we spoke with people and developed skills. We enjoyed making new relationships with peers. We also enjoyed using the voice recorders. Through this research we developed new relationships with different organisations. Probing was difficult though, and making questions from the story. To prepare the peer for the story with background work was difficult. Sometimes the recorder didn't work properly which was embarrassing. We didn't get enough practice. Some peers said that they needed their supervisor's permission [before speaking to us]. This lengthened the process. We learned how to use voice recorders. We provided guidelines on how to collect stories. It helped us a lot and we learned how to select peers. We can use this experience in future planning and especially in doing needs assessment.

A H M Kamruzzaman and Abdul Matin, community peer researchers, Bhashantek

"This is the very first time in my life I've [undertaken] any kind of research. I enjoyed it very much. I learned about the lifestyle of people with disabilities and older people. Collecting information from people with disabilities was difficult because people didn't understand what we were trying to ask them. We learned that we needed to ask permission."

Md Kamal Hossain, community peer researcher, Bhashantek

"I enjoyed going to different people's houses to collect stories. I liked the whole process. I found it most difficult writing down the stories because people had different dialects. I learned that if someone didn't want to respond, how I could convince them. If they can identify their own issues, they can bring

solutions to the community. Previously it was an activity of the media or NGOs."

Mohammad Akkas Molla, community peer researcher, Bhashantek

Other comments included:

"I felt very close and very intimate to people with disabilities and they could bring their sufferings [to us]. This is not the end. This will be shared in the post-MDG discussions. If this research wasn't done, we couldn't have gone to the people with disabilities and older people to collect stories."

"The difficulties in the action research were that we had to organise times, select respondents, plan and decide to go to people's homes. If he or she was not there, there was the challenge of having to identify [other] respondents immediately."

"The honorarium was also good."

"It was difficult to write down the dialects because we were instructed to write down exactly what people said, especially older people. They were very old. Whatever was asked they answered the same about their suffering. People with disabilities, especially children with disabilities and those with learning disabilities, their stories were a challenge and difficult to collect. We tried our best to implement what we learned in the workshop. We planned before implementing and before going to speak to people. We planned when, where and what we would ask and who would say what. We learned all these things."

"We can use our skills and do similar kinds of activity if Sightsavers, HelpAge and ADD offer similar kinds of opportunities. There's no end of learning. We need to practice more. We'd like more training opportunities. We'll try our best to conduct research in the future."



7. Conclusion

This report draws on the real-life stories of persons with disabilities and older people in Bangladesh, as told to and gathered by two groups of peer researchers in a unique participatory peer research project. The report pulls together these stories and thus provides valuable testament of the experiences of persons with disabilities and older people in one country at one moment in time, giving vivid illustration of the considerable equality and poverty challenges they face.

From these stories the peer researchers identified 13 issues that were critical to “people like them”, with significant overlap in the issues identified by the community peer researchers and the NGO peer researchers. All of the issues identified significantly affect the lives of persons with disabilities and older people, making it difficult to prioritise them in any meaningful way. As both the community and NGO peer researchers also felt that all of the issues were inter-related (for example, a lack of livelihood impacting on the ability to access health care and contributing to discrimination experienced) such a task of prioritising them may, in any case, not be possible. Nevertheless, it is possible to highlight a few key areas.

7.1 Key areas

Nearly all the stories told to the peer researchers stressed the critical issue of **insecure livelihoods**. Persons with disabilities and older people can face insurmountable barriers to finding work, with poor education and discrimination being among the factors hindering their opportunities. This results in persons with disabilities and older people having little access to income and facing the challenges of poverty and dependence that this brings. Government benefits, when they are received, do not come close to providing a livelihood. Persons with disabilities and older people often have little option but to beg if their families or communities are unwilling to support them – which the stories demonstrated, they often are.

The issue of **independent livelihoods** is also of great importance, because as so many of the stories in the research highlighted, an independent

livelihood can completely transform the way in which a person with disabilities or an older person is perceived. It enables a person with disabilities or older person to find a place in her or his household and community. Work especially, the stories showed, is a route to community acceptance and, thereby, increased confidence and self-esteem. The stories showed, that work especially is a route to community acceptance and thereby increased confidence and self-esteem

A third key area affecting the lives of persons with disabilities and older people is **poor access to services**. The stories showed that this is a result of many factors, chief among which is inaccessible infrastructure. However, discrimination, corruption, and of course, poverty also play their parts in ensuring that children and adults with disabilities and older people are very often excluded from the education, health, and transport systems. In addition, the disability allowances, pensions and other stipends to which persons with disabilities and older people are entitled are often not received because their system of distribution is corrupt or inefficient or out-of-date. Sometimes people are not even aware of their entitlements.

A fourth area that came across strongly in the stories gathered is the everyday abuse and indignity that persons with disabilities and older people in Bangladesh endure. They add up to a lifetime of **exclusion and discrimination** for those affected. Examples shared with the peer researchers ranged from name-calling to exploitation in monetary transactions to being literally pushed around on the street. Furthermore, the stories gathered in the research showed, that the family, is not always

a place of safety, with abuse being rife within households. Persons with disabilities and older people are often viewed by family members as a burden, and are often abandoned.

Abuse takes on a particularly ugly face in the form of **rape and sexual harassment** to which, the stories showed, women and children with disabilities are particularly vulnerable. The research revealed story after story of such sexual abuse and made clear that this is a deep problem for girls and women with disabilities across the country. It adds extreme hardship to the lives of girls and women who already face gender discrimination, poverty and exclusion.

A final key area identified is the issue of access to land and inheritance, where people living within insecure existences, in Bhashantek slum in particular, are singled out.

7.2 Challenges

The participatory peer research process employed in the project enabled the issues that are most critical to persons with disabilities and older people in Bangladesh to be revealed. The stories gathered detail how and why discriminatory dynamics are generated and sustained, and how they impact on people. There were also challenges in the methodology. One such challenge was people's level of awareness of intellectual impairments and mental illness. Many people who gave stories did not know the nature of their intellectual impairment or mental illness as they had never had a diagnosis. Their family members could not help establishing these facts either. This meant it was difficult to ascertain how many people had conditions they were born with and how many were mentally ill or had suffered a brain injury. In each case in the research we used the definition given by the person themselves or their family.

All the peer researchers faced challenges in their story collecting – from capturing unfamiliar dialects to keeping storytellers on track, but the evaluation comments reveal that these were far from insurmountable. As one peer researcher said: “We learned about the real lives of people with

disabilities and older people. We learned about unknown issues. We enjoyed the way we spoke with people and developed skills. We enjoyed making new relationships with peers.” A reluctance of NGO workers to express potentially negative views about their organisations was a particular challenge faced by the NGO peer researchers when collecting stories from their peers.

A final challenge faced was the sheer ambition of the project. Just over half of the stories that were collected were analysed in the workshop. Although it was ensured that the stories analysed were balanced in terms of gender, geographical representation and other relevant factors, and additional measures were taken to ensure the peer researchers felt no issue was left out, with more time and budget all the stories gathered would have been analysed.

7.3 Empowerment through research

The evaluation comments show clearly how much the peer researchers enjoyed the participatory research process. They also present how the peer researchers learned new skills and developed aptitudes and how they hope to apply these in the future.

Importantly, the research modelled the process of empowerment itself. One peer researcher said: “Sightsavers, Help Age, and ADD could have done this with graduates and educated people, but we were selected and I enjoyed that. If it was done by educated people it might have been perfect or less perfect, but it wouldn't have been the same as we did it. Another pointed out: “It was small, but it was a big thing for us.” From the moment this group of persons with disabilities and older people – from the urban slums of Dhaka and the rural villages of Cox's Bazaar – came back from gathering stories and exclaimed “we are researchers now”, the potential for real transformation was realised.

Annex 1: The guidelines for community and NGO peer researchers

Guidelines for community peer researchers

This is a guide for the community peer researchers to assist them in collecting stories in their communities.

Objectives of the research

- You are part of a participatory research project which aims to: 1) understand the experiences of persons with disabilities and older people in Bangladesh, and 2) learn about undertaking participatory research with persons with disabilities and older people.
- The research will be used by Sightsavers, HelpAge and ADD in Bangladesh and internationally as part of their advocacy to highlight the reality of the lives of persons with disabilities and older people.
- We hope that you will be able to use your learning to support your local self-help activities.

Your role as community peer researchers

We are asking you to work as a team of community peer researchers and collect stories from at least 36 people in your community between now and mid-January.

Half of these people need to be men and half women, and they need to include older people, people with physical disabilities, people who are blind or have low vision, people who are hearing impaired, people with learning difficulties and people with mental health issues.

Ethics and informed consent

Introduce yourself and explain why you are collecting stories. Ask the person if they are comfortable telling you stories and having those stories recorded (written and audio-recorded) and for their stories to be used in the research.

Either record their consent or ask a third person to witness their consent and take a note of the name and contact details of the witness.

Explain that their real name will not be used in the research

If you speak with someone under 18, please get informed consent from their parent or legal guardian.

Basic information needed

- Date of discussion
- Name
- Age
- Location
- Job
- Do they consider themselves to have a disability? If so, what?
- Mobile phone number

Story prompts

1. Tell me a story about a challenge you have faced as a person with disabilities or an older person.
2. Tell me a story about something that happened to you because you are a person with disabilities or an older person.

NB: If they talk about the incident that caused their disability, remind them they need to tell you about something that has happened because of their disability.

Follow-up questions

You can ask them follow-up questions to get more information, e.g. who else was there, when did that happen, what happened next, where did that happen?

You can also ask them why they told you this story. Is it typical or unusual? Does it happen often or to other people?

Analysing the stories

After someone has told you a story, think about who else you could speak to. Are there other people in the story who could tell you more?

Documentation

You will have a volunteer who will audio record the stories and write down everything exactly as the person says it. But you should also keep notes as well if you can.

Guidelines for NGO peer researchers

This is a guide for the NGO peer researchers to assist them in collecting stories from their peers.

Identifying your peers

Identify five to seven peers who:

Are “front line” workers – they work with older people or persons with disabilities.

You know well – you have a relationship of trust.

Please make sure you have approximately 50/50 women and men, a range of ages and they represent a mixture of different locations and types of work.

Introducing the research

Explain why you are asking your peer to tell you stories. You are part of a participatory research project which aims to: 1) understand the experiences of older people and persons with disabilities in Bangladesh, and 2) learn about undertaking participatory research with older people and persons with disabilities.

The research will be used by Sightsavers, HelpAge and ADD in Bangladesh and internationally as part of their advocacy to highlight the reality of the lives of older people and persons living with disabilities.

You have chosen to speak with them because they work directly with older people and persons with disabilities and you have a long-standing working relationship with them.

Ethics and informed consent

Ask your peer if they are comfortable telling you stories and having those stories recorded (written and audio-recorded) and for their stories to be used in the research.

Either audio-record their consent or ask a third person to witness their consent and take a note of the name and contact details of the witness.

Explain that their real name will not be used in the research – we will use pseudonyms.

When you type up the stories, save them on a computer or laptop that is password-protected to keep their stories confidential.

If you speak with someone under 18, please get informed consent from their parent or legal guardian.

Explain that you will send the write-up of their story back to them so they can check they are happy with it.

Basic information on peers

- Date of discussion
- Name
- Age
- Location
- Job
- Do they consider themselves to have a disability? If so, what?
- E-mail address
- Mobile phone number

Story prompts:

1. Tell me a story about how economic, social or political changes in Bangladesh have impacted/ influenced a person with disabilities or an older person you know.
2. Tell me a story about a person with disabilities or an older person who is unable to live the life you think they would want to.
3. Tell me a story about a person or group of people who you have been unable to support.

NB: If they talk in general terms, remind them they need to tell you a story about a real person.

Follow-up questions

Clarifying questions – to make things clear.

E.g. Who? What? Where? When?

Probing questions – to get more information.

E.g. What happened next? Who else was involved? Is this typical or unusual?

Analysis questions – to understand why.

E.g. Why did you tell me this story? Why do you think this happened? What lessons does this story give you?

Documentation

Audio record the stories and write down everything exactly as the person says it. Afterwards, listen to the audio recording and type up the stories on to your computer or laptop. Transfer the audio recording to your computer or laptop.

Email a copy of their story to the peer to make sure they are happy with the write up.

Once a month, email your stories (written and audio) to your focal point in Sightsavers, HelpAge or ADD.

Voices of the Marginalised

Voices of the Marginalised is a project bringing the perspectives of those who live in poverty or who are highly marginalised, including those with disabilities and older people, into post-2015 policy making. It is a co-collaboration between Sightsavers, HelpAge International, ADD International and Alzheimer's Disease International (ADI) in collaboration with the Institute of Development Studies (IDS).

Sightsavers

Across the world, people with disabilities are more likely to experience poverty and social discrimination. Sightsavers is committed to eliminating avoidable blindness and supporting people with visual impairments as equal members of society.

www.sightsavers.org

HelpAge International

HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.

www.helpage.org

ADD

ADD International fights for independence, equality and opportunities for people with disabilities living in poverty. We work in Africa and Asia with people with disabilities' groups in order to achieve positive and lasting change in their lives, by giving them the tools to make change happen and campaign for their rights.

www.add.org.uk

Alzheimer's Disease International

ADI works locally, by empowering Alzheimer associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia. It is the international federation of Alzheimer associations around the world.

www.alz.co.uk

Further information

To find out more about the Voices of the Marginalised project please contact: policy@sightsavers.org or consult Sightsavers website:

www.sightsavers.org/voices

You can also consult the Voices of the Marginalised Post-2015 briefing here: www.sightsavers.net/in_depth/advocacy/20045_Voices_of_the_Marginalised_Briefing.pdf

Participate

The Participate initiative is providing high-quality evidence on the reality of poverty at ground level, bringing the perspectives of people living in poverty into the post-2015 debate. It aims to bring the perspectives of those in poverty into decision-making processes; embed participatory research in global policy-making; use research with the poorest as the basis for advocacy with decision-makers; ensure that marginalised people have a central role in holding decision-makers to account in the post-2015 process; and generate knowledge, understanding and relationships for the global public good. It is co-convened by the IDS and Beyond 2015, and is funded by the UK Government.

participate2015.org

www.ids.ac.uk

