

Summary

'We can also make change'

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



April 2015





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 is the summary of the full report, entitled **We can also make change**, which presents the findings of the Voices of the Marginalised pilot research project. The report 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 aim of the research was to understand better the experiences of social, political and economic exclusion of persons with disabilities and older people in Bangladesh from their own perspectives. Although the facts of exclusion are widely documented, the reality of it is less well understood. The research uses participatory methods to explore what persons with disabilities and older people themselves understand as the causes of their social, economic and political exclusion. This is important in furthering wider understanding of poverty and exclusion as well as in determining whether the rights of persons with disabilities and older people are – or are not – being upheld.

Context

Globally, persons with disabilities face widespread exclusion. They are routinely left out from participating in social, economic and political activities and processes, including international development policy, practice and research. Exclusion reinforces the disproportionately high number of people living with disability among the poorest of the poor. There is no internationally agreed figure on the prevalence of disability in Bangladesh. However, globally 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 every year, or 1.7 per cent of gross domestic product.¹

Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) speaks of the importance of **“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, 2008).²

Global ageing has a major influence on disability trends. There is a higher risk of disability at older ages, and age-related health problems that can affect sight, hearing, mobility and mental functioning mean older people are particularly vulnerable to the poverty-related effects of disability. Bangladesh is the world's seventh most populous country and one experiencing rapid demographic change. Its population is ageing at an unprecedented rate, and more of those who cross the age of 60 are now expected to live to 75 or beyond.³

Methodology

Listening to people living in poverty in Bangladesh

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 and they are supported in the process of generating research with their peers.

The peer researchers

Two groups of peer researcher were involved in conducting the project:

1. Community peer researchers

These comprised poor and/or excluded persons with disabilities and older people from each of the two sites selected for the research: Bhashantek, an urban slum in Dhaka; and Cox's Bazar, a rural area in southeast Bangladesh. The community peer researchers were selected with consideration to their disability type, interests and gender to ensure that each of the groups was representative of its community. There were 11 community peer researchers in all: four men and one woman from Bhashantek, and three men and three women from Cox's Bazar.

2. NGO peer researchers

These comprised staff from Bangladesh non-governmental organisations (NGOs) who work with persons with disabilities and older people. The NGO peer researchers were selected with consideration to their gender and experience of poverty and/or exclusion. In addition, selection criteria included organisation type and geographical location in order to have a good geographical spread and a range of diverse local NGOs represented. People with experience of using participatory techniques and with strong peer networks that could be drawn upon were also favoured. Seven NGO peer researchers were recruited, four men and three women.

The peer research methodology

All the peer researchers were tasked with gathering stories from "people like you". As such, the community peer researchers gathered stories from other persons with disabilities and older people within their own communities; the NGO peer researchers gathered stories from other local NGO staff working with persons with disabilities and older people. Both groups of peer researchers gathered stories using prompts rather than formal interviews. Prompts were designed to be open-ended, eg "Tell me a story about a challenge you have faced as a person with disabilities or an older person." The peer researchers then jointly analysed the stories collected.

The peer researchers were supported in the processes of designing the prompts, obtaining informed consent and undertaking ethical research, and analysing the material collected through a series of research design and planning, and research analysis workshops facilitated by the IDS. Other facilitators came from Sightsavers Bangladesh, HelpAge Bangladesh and ADD Bangladesh. These workshops were held from November 2012 to April 2013. The draft research report was then verified by the peer researchers at a workshop in June 2013.

In all, the community peer researchers collected 70 stories, of which 37 were systematically analysed. The remainder were drawn upon by the researchers to validate their analysis. The NGO peer researchers spoke with staff from more than 40 different organisations, and the multiple stories that they collected were used to triangulate the data from the neighbourhoods.

A consequence of the peer research process is that any views expressed in the research belong to the peer researchers and them alone. They do not necessarily reflect the views of Sightsavers, HelpAge International, ADD International or IDS.



©Snigdha Zaman/ADD

Findings

Learning from people living in poverty in Bangladesh

As is the case with many participatory research studies, the findings from this research cannot be considered to be representative of all persons with disabilities and older people in Bangladesh. Sample selection was not random and the sample size not large enough to be statistically significant. However, the aim of the work was to understand the dynamics of exclusion – in other words, how and why exclusion happens. This could be done robustly by triangulating the perceptions and opinions of NGOs who work with persons with disabilities and older people across Bangladesh.

From the stories collected and analysed in workshops, the peer researchers identified 13 priority areas that affect persons with disabilities and older people (see Box 1).

Box 1

Priority areas affecting persons with disabilities and older people

1. Accidents and disasters
2. Livelihoods
3. Access to education
4. Medical treatment
5. Family support
6. Exclusion and mistreatment
7. Superstition
8. Access to services
9. Mobility
10. Marriage
11. Rape and sexual abuse
12. The role of grassroots community-based organisations

The main findings for each priority area, along with recommendations made by the peer researchers during workshop discussions, follow:

1. Accidents and disasters

Many people in Bangladesh become disabled as a result of accidents and natural disasters. Additionally, poor people are more likely to become disabled following an accident or natural disaster due to the difficulties in accessing medical treatment (see 4. Medical treatment).

Persons with disabilities and older people face a higher risk of being injured in an accident than other people. For example, roads are particularly hazardous for people with visual impairments. During natural disasters, they are more likely to suffer injury and can have difficulties reaching shelters to protect themselves.

Peer researcher recommendations

- Local government and NGOs to run natural-disaster awareness campaigns which emphasise the importance of prioritising persons with disabilities and older people in relocation and rescue efforts.
- Ensure information about disasters is available in accessible forms, including Braille and sign language.
- Run accident-awareness campaigns, for example on traffic safety, to prevent and reduce the risk of accidents.

2. Livelihoods

The lack of a livelihood was an issue that appeared in nearly all the stories collected by the peer researchers. Finding a job in such a populous country as Bangladesh is difficult for everyone, but especially so for persons with disabilities and older people.

There is a 10 per cent public sector jobs quota for orphans and persons with disabilities, but orphans are often preferentially chosen to fill these posts over persons with disabilities. Even for educated persons with disabilities, finding a job is hard. On occasion, they are asked to pay bribes.

“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. Community peer researcher, Cox’s Bazar

Self-employment can be an alternative but access to affordable credit to start businesses is difficult for persons with disabilities and older people. Banks and NGOs offer loans, but the sums involved can be insufficient. Sometimes, loans bring with them repayment problems or families exploit loan systems for their own benefits.

Many persons with disabilities are unaware of disability allowances. These are, in any case, limited in number. Corruption also surrounds their distribution. For example, people have to pay to obtain the application forms for them. On occasion, people bribe officials to receive these allowances when they are working. This is also the case for older people, who cannot get jobs and often do not have a pension. The list of older people to whom pensions are distributed is out of date. For those who do receive a pension, the amount is insufficient to live on. In addition, older people are often not eligible for loans to start their own businesses.



Begging is therefore not an option for both persons with disabilities and older people, but often the only way to obtain food to survive. This is especially so if they have no education or no family to support them.

“If an older person has no land, no family, no education, no money, they have to beg. Now I can’t walk about. I’ve become a lot weaker... for the past year I’ve not been able to work.”

Mamun, 65. Bhashantek

Urban and rural areas offer very different livelihood opportunities. Industrialised urban areas offer better job prospects than rural areas, and it is harder to make a living begging in rural areas than in towns and cities. People who live alone in rural areas often ask their neighbours for money because begging alone does not bring in enough. The lack of support for older people in rural areas who can no longer farm as a result of ageing is also an issue. No support is available for them.

The ability to earn a livelihood, however, brings with it positive regard and greater acceptance from family and community. Almost all the positive stories of persons with disabilities and older people who were able to stop 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 started to give him work and understood that he can do this work.”

Nazrul Islam. NGO story

Peer researcher recommendations

- Create lists of persons with disabilities and older people to facilitate the distribution of allowances and pensions.
- NGOs to advocate with social welfare officers and the Ministry of Social Welfare for a transparent pensions and allowances system monitored by the District Disability Federation.
- Broaden availability of loans from the Ministry of Social Welfare to persons with disabilities and older people.
- Offer skills training rather than cash grants to persons with disabilities and older people.
- Ensure skills trainers are themselves equipped to train persons with disabilities, eg in the use of sign language.
- Separate public sector job quotas for persons with disabilities from job quotas for orphans.
- Lower the education levels required for public sector jobs for persons with disabilities.
- Introduce job quotas in the private sector for persons with disabilities.

3. Access to education

In spite of government claims that education is free, schooling in reality costs several hundred taka a year. Persons with disabilities and older people cannot afford school fees for their children because of their lack of access to a livelihood (see 2. Livelihoods).

There are education stipends for children with disabilities, but these are limited in number and their distribution is often determined by nepotism, patronage and other corrupt means. Central government is committed to enrolling children in schools, but access to education for children with disabilities is hindered by a lack of local monitoring. In addition, local officials are sometimes unaware of the rights of children with disabilities.

Some parents, particularly those who are uneducated, are unaware of the value an education can bring their children. They may, for example, believe a child with disabilities is better off at home, where she or he may be able to undertake domestic duties; or they may believe a child with disabilities is incapable of learning.

There are few special schools for children with disabilities, and only a few of these are free. Competition for a place is high. In addition, poor parents are often unaware of their existence. The situation for children with disabilities in rural areas is particularly acute. Special schools are only available at divisional level and there are costs attached. Girls with disabilities, too, face added difficulties obtaining an education. For example, government schools for children who are blind or have low vision are only for boys. Families are also less likely to send their girls with disabilities to school. This may partly be a result of gender discrimination, but may also be because families fear for their girls' safety out of the home as sexual harassment is widespread (see 12. Rape and sexual harassment).

Those children with disabilities who do go to school can face additional barriers to learning. For example, if they have hearing or visual impairments, they often find it difficult to follow lessons. Disability is now on the teacher-training curricula, but there is still a lack of suitably trained teachers. Besides, although all government primary schools now provide ramps, many classrooms remain inaccessible or unsuitable

in other ways for children with physical disabilities. The high teacher-to-child ratio in Bangladesh schools – which is sometimes as high as 1:100 – adds to the difficulties of children with disabilities.

Bullying and discrimination at school can also be an important issue.

“Children used to tease and beat [my grand-daughter]. She couldn't concentrate on the class work for long... in school her classmates disturbed her in every way... Sometimes she cries out while sleeping. She wants to study at home and she sits with her books. But when she cannot read, she gets frustrated... Everyone is worried about her future. After all, she is a girl and how will she survive?”

**Grandmother of Abida, 13.
Cox's Bazar**

Peer researcher recommendations

- Ensure that people sitting on school management committees are aware of the rights of children with disabilities.
- Improve monitoring of the school enrolment rates of children with disabilities.
- Provide additional facilities and teaching materials for children with disabilities.
- Provide more and better training for teachers on working with children with disabilities.
- NGOs and donors to promote inclusive education to government and NGOs; and donors to work more closely with government.
- Establish more special schools, eg for children who are blind or have low vision.
- Ensure educated persons with disabilities have access to employment, as education is closely aligned to the issue of livelihoods.
- Run awareness-raising activities with families of children with disabilities stressing the value and potential of education.
- Introduce incentives to send children with disabilities to school.



4. Medical treatment

Government hospitals are often too far from where people live for persons with disabilities and older people to access them, while private clinics are too expensive for them.

“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.
Community peer researcher, Bhashantek

Government hospitals, when they can be accessed, also present problems for persons with disabilities and older people. Corruption means younger people and those who can afford bribes are best placed to access treatment. The quality of medical treatment is also variable, with mistreatment, poor treatment and medical staff’s lack of understanding of disability often cause for complaint.

As a result, persons with disabilities and older people often fail to receive medical treatment, receive the wrong treatment or seek treatment from alternative or traditional practitioners.

“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 Khan, 22. Cox’s Bazar

Peer researcher recommendations

- Educate doctors in appropriate behaviour when treating persons with disabilities and older people.
- Train community-level health care workers to give proper treatment to persons with disabilities and older people.
- Prioritise persons with disabilities and older people for hospital treatment.
- Offer separate and special facilities in hospital to support persons with disabilities and older people, eg signage in Braille.

5. Family support

For older people, the lack of family support is a pervasive problem. Families often view their older members as a burden, especially when they are not earning. Sometimes older family members are abused; sometimes they are abandoned. The situation for older people who do not have sons is particularly acute as traditionally sons stay with their families when they get married, while daughters move in with their in-laws.

“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, 70. Bhanshantek

Older people are often ashamed of the circumstances they find themselves in.

“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, 70. Cox’s Bazar

The situation for older people in rural areas, where the practice of supporting neighbours persists, can be better than in urban areas.



©Tim McDonnell/Sightsavers

Families often neglect and fail to support members who have disabilities too.

“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, 55. Cox’s Bazar

Peer researcher recommendations

- Establish community-managed shelters for older people who have no families.
- Educate persons with disabilities and older people so that they understand that their problems are not of their own making.
- Create and support job opportunities offering financial independence to persons with disabilities and older people.

6. Exclusion and mistreatment

Abuse from community members is common. Persons with disabilities often have to endure teasing, name calling and being pushed around. They also can be exploited, with for instance, persons with visual impairments being particularly vulnerable to being cheated in money transactions. Persons with disabilities and older people can also suffer at the hands of their families, who consider them a burden.

“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 girl or woman who is blind or visually impaired] and uses slang... He knew about my condition before getting married to my daughter, but now he doesn’t care.”

Abida, age not known. Bhashantek

Even without these abuses, persons with disabilities are excluded from participating fully in society.

“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, 18. Cox’s Bazar

Exclusion is worse for girls and women with disabilities, who are often hidden away in the home.

“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 to the market with me.”

Laboni, 55. Cox’s Bazar

Older people too experience mistreatment, exploitation and exclusion. Those with many children can suffer particularly badly as each child tries to pass on responsibility for their older relative to her or his siblings. Again, the situation for older women is worse. As women have no property rights, an older woman without a husband is particularly vulnerable. In addition, people can shun widows. They are not welcome at weddings and other events as people believe their presence is bad luck.

Peer researcher recommendations

- Run public awareness campaigns to educate people in the rights and capabilities of persons with disabilities and older people. Co-opt influential people, such as members of shalish committees (informal village community hearings), into these campaigns.
- Create productive work and income-generating activities for persons with disabilities.
- Make bank notes easy to identify for persons with visual impairments, for example by having different denomination notes in different sizes or printing them in Braille.

7. Superstition

Society generally looks down on families in which a member has disabilities. Superstitions about disability and the causes of disability are widespread, particularly in rural areas. For example, many people believe that disability is caused by bad spirits; others that a child's disability may be caused by the parents having sinned or cheated in some way.

Superstition can extend to contact with persons with disabilities. For example, sometimes children who do not have disabilities are prevented from playing with children with disabilities as it is believed the contact will bring disability upon them.

“I went to [the boy] and when I sat near him I smelt a bad smell. His condition was 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... 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

Superstition about the bad luck disability brings can also extend across families. For example, sometimes the marriage prospects of the sibling of a person with disability are affected.

Superstitions surround illnesses and conditions associated with ageing too. For example, in rural areas cataract is believed to be the result of people having sinned with their eyes. The sudden onset of illness in an older person is sometimes seen as the result of having sinned as an adolescent.



©Snigdha Zaman/ADD

Peer researcher recommendations

- Convene meetings with community and religious leaders to discuss disability and ageing.
- Educate teachers in schools and madrasas (Islamic schools) about disability and its causes.
- Run a public information campaign about disability, explaining the causes of disabilities, the rights of persons with disabilities and the valuable contribution persons with disabilities can make to society.
- Use mass media and technology to disseminate positive messages about persons with disabilities and older people.
- Improve treatment to pregnant women to lower their risks of having a child with a disability.

8. Access to basic services

Older people fail to get their needs met as health care prioritises reproductive health care and younger women. Health professionals too are not trained to meet the health needs of older people, who are often put off accessing health care because of the poor attitudes they face. Sometimes older people fail to raise their health needs because they fear being a burden.

Similarly, persons with disabilities often have to deal with medical professionals who have little knowledge of disability. There is, in particular, a lack of services for people with mental illnesses and intellectual impairments.

Hospitals, schools, transport and recreational activities all lack specially adapted infrastructure and facilities, making access to a wide range of services for persons with disabilities and older people difficult or impossible.

Peer researcher recommendations

- Establish separate facilities in hospitals for persons with disabilities.
- Make public transport accessible for persons with disabilities and older people.
- Make all public offices physically accessible for persons with disabilities and older people.
- Ensure buildings and facilities where community events take place are fully accessible, for example community centres where marriages take place.
- Provide legal services for persons with disabilities and older people.



9. Mobility

A lack of accessible public transport means that mobility is an important problem for persons with disabilities and older people. For example, in Cox's Bazar people must be able to climb stairs to use the buses. Buses also often fail to stop fully at bus stops, making it difficult to get on and off vehicles. The expense of specialised equipment such as wheelchairs, and the lack of availability of spare parts for such equipment, is an added difficulty faced by persons with mobility issues.

People with visual impairments can use white canes or have sighted guides, but others prefer not to as the use of canes or guides can lead to bullying and ridiculing. In addition, long, white sticks are difficult to use. Government-issued white canes often break.

“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, 66. Bhashantek

A lack of mobility means persons with disabilities and older people are often unable to access toilet facilities.

“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, 30. Cox's Bazar



©Peter Caton/Sightsavers

Peer researcher recommendations

- Run a public awareness campaign about accessibility and public transport.
- Ensure persons with disabilities and older people have priority when getting on buses.
- Allocate priority seating on buses for persons with disabilities and older people.
- Install lifts, ramps and railings in public buildings to support the mobility of persons with disabilities and older people.
- NGOs to ensure traffic police and transport and infrastructure departments are aware of the needs of persons with disabilities and older people when planning and building.
- Widen the provision of white canes for people with visual impairments.

10. Marriage

Bangladesh is a male-dominated society, with women being marginalised and discriminated against. The situation for women with disabilities is particularly harsh. They are often hidden away inside the home where their situation remains unknown to the rest of the community.

Many men do not want to marry women with disabilities. It is seen as shameful and it is widely believed that women with disabilities are unable to manage household activities. People also fear that the children resulting from the marriage will also have disabilities. Hence, it is hard to arrange a union for women with disabilities and the dowry is high.

“I couldn’t marry, I couldn’t enjoy my life and I couldn’t have a family.”
Laboni, 55. Cox’s Bazar



©Snigdha Zaman/ADD

However, a man may sometimes marry a woman with disabilities in order to access her family land. Some beggars marry women with disabilities in order to find shelter. Women with disabilities who do marry are often vulnerable to abuse. If women become disabled when they are already married they also often face abuse, and sometimes abandonment.

“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... He married me before I was disabled.”
Tamanna, 55. Cox’s Bazar

Conversely, men who have disabilities can be an attractive marriage proposition as they can beg to earn a living. Men from families with money can also buy a bride from a poorer family.

Peer researcher recommendations

- Improve education and vocational training for women with disabilities so they are better able to negotiate a marriage as well as be financially independent (financial independence will lead to greater community respect and better marriage prospect).
- Create public sector job opportunities for women with disabilities.
- Promote positive images of women with disabilities in the media.

11. Land

Persons with disabilities and older people in Bhashantek slum experience great insecurity as a result of lacking their own land or the money to buy it. They cannot afford the rents for apartments built as part of a government rehabilitation project. Corruption, in any case, often lies behind their allocation.

“I’m living like a nest-less bird. I have debt. I have to survive by begging. I live on government land.”
Dewan, 66. Bhashantek

“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, 70. Bhashantek

Where land and homes are owned, the siblings of men with disabilities are often favoured when it comes to these assets being inherited. Women generally do not inherit land so widows with disabilities must depend on their sons and unmarried women with disabilities on their brothers. Besides, the law does not allow people with intellectual impairments to own land.

Peer researcher recommendations

- Provide subsidised government land for persons with disabilities and older people. NGOs to lobby government for this provision.
- Increase spending on government rehabilitation programmes for beggars.
- Provide government sheltered care homes for older people.



©Snigdha Zaman/ADD

12. Rape and sexual harassment

The NGO peer researchers heard many stories of the rape and sexual harassment of girls and women with disabilities. It seems to be common and often takes place within families or households. Those with visual, speech or intellectual impairments, as well as children, are most vulnerable.

Justice is hard to obtain. Providing evidence of rape can be difficult. For example, court lawyers do not understand sign language. Going through the court process is also emotionally taxing for victims. In many cases, the abusers are powerful and influential, again making justice difficult to obtain.

“[People] said that she was the result of her parents’ sins. People called her deaf and mute and neglected her. She cried a lot at times. Because she was disabled and poor, she couldn’t study... 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. 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

Sometimes, locally-arranged settlements result in abusers giving money to victims’ families, or victims being forced to marry their abusers.

The community peer researchers did not collect any stories about rape or sexual harassment.

This discrepancy prompted a workshop discussion with the community peer researchers agreeing that girls and women with disabilities are more vulnerable to rape and sexual harassment, though the shame associated with these abuses meant it was not spoken about openly.

“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?”

**Hafez Mohammad Jafar Alam.
Community peer researcher,
Cox’s Bazar**

Peer researcher recommendations

- Village justice committees to run education campaigns, in particular emphasising that sexual crimes transgress religious values.
- Create committees on violence against women at union or sub-district level.
- Carry out public punishments on perpetrators of rape and sexual harassment to discourage others.
- Strengthen and speed up the legal system.
- Provide protection for witnesses and victims of rape and sexual harassment.

13. The role of grassroots community-based organisations

The NGO peer researchers heard several critical stories about the role of NGOs and community-based organisations supporting persons with disabilities and older people. NGOs support the wrong income-generating activities or fail to do a proper needs assessment before giving cash. They also lack accountability and the “rights-based approach” of these organisations is questionable.

“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.”

Al Amin. NGO peer researcher

“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.”

Lipi Rahman. NGO peer researcher

Community support is required for successful initiatives with persons with disabilities and older people, though many projects lack sustainability, and the priorities of NGOs can be misplaced.

“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.”

NGO peer researcher

One of the more effective roles that NGOs can play is to set up pilot projects that can later be taken up by government. The Centre for Disability and Development is a good example of this, with a satellite therapeutic service set-up through mobile phone. This initiative is working well and has been taken up by the Ministry of Social Welfare.

The lack of persons with disabilities, and in particular women with disabilities, on committees is an issue. This is a result partly of gender discrimination, but also practical issues such as the lack of toilet provision for women.

The community peer researchers did not collect stories about the role of grassroots organisations and the issue failed to come up in their discussions. A later workshop discussion around this saw the community peer researchers expressing a number of negative views around NGO activities.





©Snigdha Zaman/ADD

“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’ [daily allowance] for government officials to come to meetings. Why isn’t it given directly to people with disabilities?”

Hafez Mohammad Jafar Alam.
Community peer researcher, Cox’s Bazar

Peer researcher recommendations

- NGOs interventions to prioritise livelihoods, and in particular regular incomes, for persons with disabilities and older people.
- NGOs to involve communities more in their interventions.
- NGOs to prioritise long-term programmes over short-term projects.
- NGOs to set up pilot programmes which can later be taken up by government.
- NGOs to include persons with disabilities and older people on committees, and in particular women with disabilities and older women.
- NGOs to spend more on capacity-building and participation.
- NGOs to offer more training and employment opportunities to persons with disabilities.



Conclusion

The stories gathered by the community peer researchers of Bhashantek and Cox's Bazar and the NGO peer researchers for the Voices of the Marginalised project tell of the experiences of persons with disabilities and older people in one country, at one time. As such, they provide valuable testament to the considerable equality and poverty challenges persons with disabilities and older people face in a particular context. The detail of the testimonies reveals how and why discriminatory dynamics are generated and sustained, and how they impact on people.

There was significant overlap in the 13 issues identified as critical to persons with disabilities and older people. In addition, the peer researchers felt that all the issues identified were inter-related. For example, a lack of livelihood impacted on the ability to access health care and so contributed

...the stories gathered illustrate how transformative an income can be in terms of independence, status and self-esteem.

to discrimination. Prioritising the issues identified may not be possible. Nevertheless, it is possible to highlight a few key areas.

Chief among them is 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, mainly 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. Abuse takes on a particularly ugly face in the form of rape and sexual harassment to which, the stories show, women and children with disabilities are particularly vulnerable. This adds extreme hardship to the lives of girls and women with disabilities who already face gender discrimination, poverty and exclusion.

Lack of education of children with disabilities is a contributing factor to extreme poverty when they reach adulthood.

Lack of education of children with disabilities is a contributing factor to extreme poverty when they reach adulthood. It also perpetuates the belief that children with disabilities are unequal to those children without disabilities. Finally, the people living in Bhashantek slum in particular

singled out land, and the difficulty of access to it, as an issue.

The community and NGO peer researchers demonstrably enjoyed the participatory research process. They learned new skills and developed aptitudes which many of them said, in their evaluation comments, they hope to further apply in the future. Importantly, the research also 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.

Overall recommendations

Sightsavers, HelpAge International, ADD International and Alzheimer's Disease International as well as IDS believe in the full and equal participation of persons with disabilities and older people in developing and negotiating the post-2015 development agenda. Their experiences are what count in working towards a rights-based framework for all and a more positive future for persons with disabilities and older people in particular.

Based on the findings of this participatory research study, the recommendations of the peer researchers, and our own experiences as organisations working for the rights of persons with disabilities and older people, we have drawn specific recommendations.

Policy makers must:

1. Ratify and implement the UN Convention on the Rights of Persons with Disabilities (UNCRPD); and support the elaboration of a UN Convention on the Rights of Older People (UN CROP).
2. Ensure that age and disability are treated as crosscutting themes in all post-2015 development goals; and support improved disability and older-person data gathering and analysis mechanisms.
3. Promote the full and equal participation of older people and persons with disabilities in social and political life.

Policy makers must further:

1. Extend social protection floors to secure income for persons with disabilities and older people.
2. Prioritise equitable livelihood interventions to support services provided by the State.
3. Ensure access to effective, safe, affordable or free quality health services to those that need them, when and where needed.
4. Ensure an inclusive approach to education that reduces stigma and discrimination for children with disabilities and promote and provide opportunities for lifelong learning for all.
5. Implement justice reforms aimed at ensuring equality of property, land and inheritance rights for persons with disabilities and older people.
6. Implement legislative, social and educational measures that protect older people and persons with disabilities, particularly women, both within and outside the home, from exploitation, violence and abuse.
7. Prioritise the rights and needs of older people and persons with disabilities in disaster risk reduction and emergency programmes.
8. Commit to campaigns aimed at raising awareness of the real-life experiences of older people and persons with disabilities.
9. Promote further participatory research to ensure the voices of older people and persons with disabilities are heard.

Endnotes

1. World Health Organization (2011) *World Report on Disability 2011*, Geneva: WHO
2. UN General Assembly (2008) *UN Convention on the Rights of People with Disability*, New York, UNGA
3. www.helpage.org/where/bangladesh

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 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, and receive the full report please visit

www.sightsavers.org/voices or contact policy@sightsavers.org

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

