‘We can also make change’

September 2013

A briefing based on ‘We can also make change’ a report from Voices of the Marginalised, a research project in Bangladesh
Voices of the Marginalised

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

Sightsavers
Sightsavers works to combat blindness in developing countries, restoring sight through specialist treatment and eye care. It also supports people who are irreversibly blind by providing education, counselling and training. It helps the people who need it most – those living in poverty in some of the world’s poorest countries.
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 works in partnership with disabled people and their organisations in some of the poorest countries in Africa and Asia by encouraging disabled people to come together to channel their voices and campaign for their own 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.

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.

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.
Summary

This briefing draws on the real-life stories of persons with disabilities and older people in Bangladesh, as told to researchers in the Voices of the Marginalised project entitled “We can also make change”. The stories tell of the experiences of older people and persons with disabilities in one country, at one moment in time, providing valuable testimony of the considerable equality and poverty challenges they face – in particular in securing livelihoods; accessing public services; living free of discrimination, bullying, harassment and violence; and accessing justice.

However, it is widely – if perhaps not as vividly – documented elsewhere that persons with disabilities and older people experience similar challenges throughout the developing world. Much remains to be done to promote and achieve their full participation in political, economic, social and cultural life.

If there is one message only from the stories heard in this research, it is of the vital importance of 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 our own experiences as organisations working for the rights of persons with disabilities and older people, we have drawn specific recommendations:

Central recommendations:

Policymakers 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.
2. Ensure that age and disability are treated as cross-cutting 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.

Further recommendations:

Policymakers must:

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.
The challenge

Up to 20 per cent of the world’s population lives with some form of physical or mental disability or mental health impairment, with developing countries being home to 80 per cent of persons with disabilities. Persons with disabilities face well-documented political, economic, social and cultural barriers. They are more likely to live in poverty and to live on the margins of society, facing obstacles to full participation in their communities and the wider world. In Bangladesh, where the real-life stories in this briefing come from, the rate of disability runs at more than 30 per cent. This represents a significant equity challenge for policymakers and development professionals.

There are economic considerations too. The cost of disability as a result of lost income in Bangladesh due to a lack of schooling and employment for persons with disabilities and their carers is estimated at US$1.2 billion annually, or 1.7 per cent of gross domestic product. It has been estimated that developing countries experience from 12 to 20 per cent of their population as non-productive due to disability.

Older people too experience disproportionate levels of poverty and marginalisation. Many may not consider themselves to have a disability – considering the challenges they face, for example failing sight and mobility, as natural accompaniments to ageing. However, the disadvantages older people experience strongly mirror those of persons with disabilities.

By 2030, 16.6% of the world’s population will be aged 60+. 73% of these will live in developing countries.

Story of a girl with disabilities

“[People] said 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. 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.”

As told to an NGO peer researcher

Post-2015 – a new opportunity

A sustainable and prosperous world is one in which people of all ages and all abilities are supported throughout their lives. The Millennium Development Goals (MDGs) have enabled important progress in human development through highlighting poverty, hunger, maternal and child health, HIV and AIDS, education and aid disbursement. However, they contained no explicit reference to persons with disabilities and older people, despite the principles of human dignity, equality and equity for all having been identified as fundamental in the 2000 Millennium Declaration.

The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006, though this remains to be ratified by all UN Member States. The need for an international human rights instrument dedicated to the rights of older people is currently being discussed by UN Member States. The post-2015 development framework represents a new opportunity to recognise fully the rights of older people and persons with disabilities. Doing so will demand political determination, investment and policy innovation, but without this equitable global development is not possible.
Effective policy responses which tackle poverty and inequalities for people of all ages and abilities also demands a commitment to listen to the experiences of people affected by disabilities and ageing. Participatory research, which aims to break down the divide between researchers and researched, is one way in which this can be achieved. It is the methodology behind “We can also make change”, the Voices of the Marginalised research informing this briefing.

The stories captured were all collected through participatory research involving older people living in poverty or persons with disabilities living in poverty from two communities in Bangladesh: Cox’s Bazar, a rural community in the south-east of the country, and Bhashantek, a slum area of Dhaka; as well as local NGO workers experienced in working with older people and persons with disabilities, some with disabilities themselves. These people, selected because of their direct experience of poverty and/or exclusion (and being a gender-balanced group), interviewed their peers and analysed the stories they were told. They were facilitated in this by researchers from the Institute of Development Studies (IDS), UK.

The objective was to bring the perspectives of those who live in poverty or who are highly marginalised, including persons with disabilities, older people and persons living with mental health issues, into the post-2015 policymaking process – ensuring that their human rights are explicitly considered in any future development framework. The full report of the research – entitled by the researchers ‘We can also make change’ – will be published later this year.
Listening to people living in poverty in Bangladesh

The following key areas emerged from the stories heard in the Voices of the Marginalised project in Bangladesh.

Livelihoods insecurity

Persons with disabilities can face insurmountable barriers to finding work; poor education and discrimination, among other factors, hindering their opportunities. They may have little option but to beg if their families or communities are unable or unwilling to support them. For older people too, livelihoods can be fragile and older people are often dependent on their children, and on sons in particular. Pensions and stipends, where they exist, are largely inadequate. Persons with disabilities and older people are commonly viewed as a burden on the household. Often they are abandoned. Many move to urban areas where the opportunities for begging are greater.

“Sometimes my sons give me a lot, sometimes they do not.” Kamrul, aged 78

“If an older person has no land, no family, no education, no money, they have to beg. Now I cannot walk about. I have become a lot weaker … for the past year I haven’t been able to work … Why will my daughters help? I have married them off … They themselves can barely manage, how will they look after me?” Mamun, aged 65

“I am living by borrowing from other people and relatives here and there. I am just surviving. I only get the disability allowance [300 taka per month].” Imran, aged approximately 45

“All of 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 … Only having one hand is a pain for me.” Sujan, aged 18

Loans to start small businesses are one means by which older people and persons with disabilities can initiate independent livelihoods. However, NGOs and banks can be reluctant to extend credit. Interest rates can also be high and sometimes security is required, which few have access to.

Skills training and quotas are other routes to jobs. However, such initiatives have often proved ineffective.

Land and property rights

Insecure livelihoods are exacerbated by a lack of property and land rights – either in law or by common practice. Existing inheritance and property laws discriminate against women and people with intellectual impairments are barred from owning land. It is also common for people with disabilities not to inherit land and homes, with assets being divided up among their non-disabled siblings. As such, persons with disabilities and older women find themselves at the mercy of their families for shelter and security.

Work and dignity

Work is not only a means to an independent livelihood. It is a route to community acceptance. One 60-year-old woman received financial help to open a shop:

“The chairman of the elders committee managed an elderly allowance card for [this woman] and she received the money in a lump sum after six months. She opened a shop – 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. They told her to repay it on a monthly basis. The elders started to do their business with this woman shop to increase her sales and their profit. Now she attends meetings, and as her social status has increased since joining the elders committee her courage has increased too.”

As told by NGO worker Hosne Ara Khuku
Poor access to public services
The twin effects of discrimination and poverty mean older people and persons with disabilities are frequently unable to access public services.

Health care
In health care, younger people and those with influence obtain priority treatment. In rural areas, government hospitals can be some distance away and nearer private clinics are unaffordable. Even in government hospitals, sometimes brokers must be paid to jump long queues.

“My daughter cannot speak. She cannot hear. She cannot go out of the house. She beats people, she is violent and people judge her. I am worried, but what can I do? She has been born into a poor family.” Mother of 26-year-old Shoma, who has multiple physical and intellectual impairments

“I suffered a stroke a year ago and since then I’ve been very sick. I even stopped talking … I don’t have any money. How can I see a doctor? My legs and hands are very weak, I feel pain, there is no strength left in me.” Rupa, aged 65

“[My son’s father] has been sick these last three years. We’ve spent a lot of money on his treatment. We hardly pass a day without borrowing [money] from people. That’s why we haven’t taken my son for treatment.” Mother of 7-year-old Parvaz, who has speech impairment

“For just a [hospital] appointment, it costs 20 taka, but any tests or medicine are extra. We cannot afford it and we come back without being treated.” Mohammad Akkas Molla, community peer researcher

Girls and education
Access to education is particularly difficult for girls with disabilities. Even when their families send them, discrimination and bullying can be a problem.

“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. As a response, she quarreled with them and returned home alone. ... 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 13-year-old Abida

In Bangladesh, health systems prioritise maternal and neonatal health, and gerontology and geriatrics are relatively new disciplines. In addition, doctors are perceived as having little understanding of disabilities. For example, when a man in a wheelchair sought treatment at a hospital for fever, the consulting doctor assumed that the wheelchair was being used for the fever. There is very little, if any, provision for people with mental illness or people with intellectual impairments.

Education
There is a limit on the number of stipends available to people, and patronage and corruption mean that these often go to wealthy or influential families. There are few specialised facilities for children with disabilities and teachers are not trained in disability issues.

Ignorance also affects children’s educational opportunities. Parents of children with disabilities have few expectations of them. Sometimes children with disabilities are denied access to school because it is widely thought other children will be afraid of them.

Infrastructure
Hospitals, schools and other public buildings are often effectively closed to older people and persons with disabilities as they are inaccessible, lacking ramps, lifts and railings for access. The public transport system too is often out of bounds for people with mobility issues. Buses are often only accessed via a high step, priority seating is limited or non-existent, and sometimes passengers are expected to jump on and off moving vehicles. Public communications are often not available in braille and other accessible formats.

Disaster risk management
Natural disasters, such as floods, present particular difficulties for older people and persons with disabilities, who find it difficult to reach shelters. Older people are often left in the home to take care of belongings.

Disabled women’s organisations are very active to ‘make a change’.
Bullying and violence

Discrimination, intimidation, harassment and violence are everyday experiences for persons with disabilities and older people, who often find that there is no respite from such abuse even in their home life. Name-calling is common, as is scapegoating.

“My daughter cannot bathe herself and neither can she comb her hair ... She cannot use her hands for anything ... That is why her younger brothers beat her, and even neighbours bully her. People ask, ‘why is your daughter like this?’ ... [They] talk in an ugly manner and make ugly remarks.” Mother of nine-year-old Megh

“Everybody calls me ‘langra’ [a slang term for someone with a disability]. My parents and brothers and sisters call me langra ... It hurts me when they call me langra.” Nipu, aged 15

“[People] 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 am blind.” Abida, age not known

Sexual abuse

Women and children with disabilities are vulnerable to sexual abuse, and those with visual and speech disabilities or learning impairments particularly so. Again, the family is not always a place of safety, with family members often the perpetrators of abuse. The stigma of rape or the threat of reprisal can be enough to silence victims, even when they are able to communicate. When crimes are reported, justice is rare as criminal justice mechanisms tend to bias against persons with disabilities having their experiences heard. Power and influence are often wielded to protect abusers.

“[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

Exploitation

Persons with disabilities and older people are also often exploited. For example, people who are blind or have low vision find they are easy prey for tricksters. They are particularly vulnerable in monetary transactions because small and large denomination bank notes can look similar. Persons with disabilities being tricked out of family land and property is a common occurrence.
Discrimination and exclusion
The cumulative effect of the multiple challenges faced by persons with disabilities and older people is a life of discrimination and exclusion from equal participation in all aspects of society. People with disabilities and older people can find they are unwelcome, for example, on village committees, or denied access to platforms where they may speak freely about the issues affecting them. Sometimes, when development projects allow for participation of older people or people with disabilities, these opportunities end when the projects end.

Exclusion is particularly acute for older women and women with disabilities, who are often hidden in the home. Finding a husband can be hard. Their dowries are higher and families often believe their disabilities will be inherited by any children of the marriage.

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

Myths and misunderstandings
Ignorance is widespread. Disability is often seen as the result of evil spirits (jinn) or sin. Some disabilities are believed to be ‘catching’, or contact with a person with disabilities to bring bad luck. People commonly believe that persons with disabilities are unable to learn or to work. One NGO worker visited a village in a rural area where he found a boy with disabilities:

“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 going to die. 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 boy’s 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 worker
Our recommendations

As a priority, the UN Convention on the Rights of Persons with Disabilities (CRPD) should be ratified and implemented by all UN Member States, and the elaboration of a UN convention on the rights of older people should be supported. These actions need to be accompanied by a commitment to ensure that the rights of older people and persons with disabilities are a cross-cutting theme in all post-2015 development goals. To monitor development and hold governments accountable, data disaggregated by age, gender, ethnicity and disability must be an overarching aim of post-2015, with a clear understanding that no goal is recognised as having been met without it being demonstrably met for all social groups. The current lack of relevant statistical data creates difficulties in effectively and accurately planning programmes and creating policies.

The testimonies in Voices of the Marginalised highlight the extent of financial, physical and social abuse; bullying and violence; and discrimination and exclusion that people in Bangladesh experience as a consequence of their age and/or disability, with gender being a powerful compounding factor. These are big challenges within families as well as within the labour market, health and education systems, and access to justice, and they need to be addressed at many levels.

Livelihoods security

Bangladesh in particular must proceed with the full implementation of the International Labour Organization’s decent work agenda and extend the provisions of social security and services for all, by implementing the Social Protection Floor endorsed by UN agencies and UN Member States. Bangladesh approved this recommendation through the Ministry of Labour in 2012. The ‘leave no one behind’ paradigm advocated for by the High Level Panel report, needs to extend to prioritising secure income for persons with disabilities and older people through the extension of a nationally-owned, human rights based social protection floor. Livelihoods interventions by the state, private sector or civil society can further support people to live beyond the minimum and increase their independence.

Access to social security is furthermore formulated in Article 15 of The Constitution of the People’s Republic of Bangladesh: It shall be a fundamental responsibility of the State to [secure] to its citizens the right to social security, that is to say to public assistance in cases of undeserved want arising from unemployment, illness or disablement, or suffered by widows or orphans or in old age, or in other such cases.

Accessing public services

Good health helps older people and people with disabilities escape from poverty and provides the basis for long term economic development. Older people and persons with disabilities often experience poorer levels of health than their peers. Often for people with disabilities this can be linked to their impairment but also commonly due to a lack of accessible health facilities, information or barriers to treatment or discrimination.

Inequities in access to health care add particular challenges to older people and persons with disabilities who are very often in great need of quality health services. Free or affordable access to health services must be implemented, and health workers trained and supervised to care for and treat older people and persons with disabilities. This is especially important as population ageing in Bangladesh and elsewhere in the developing world is leading to increased life expectancy, and disease patterns are shifting to more non-communicable diseases such as diabetes, hypertension, cancer and dementia.

Children with disabilities face immense obstacles accessing education. When children with disabilities are excluded from education their future economic prospects are severely restricted, contributing to a cycle of inter-generational poverty as they establish their own households.

Bangladesh and other developing countries need to take steps to implement an inclusive approach to education that reduces the stigma and discrimination that contributes to children with disabilities being
persons with disabilities should be prioritised in disaster
violence and abuse.

Ending bullying and violence

Full and equal land and inheritance rights for older people and people with disabilities are commonly denied, and
are put in place to
combat payment for services (corruption and bribery) in both the health and education sectors. Also in access
to stipends, pensions and government schemes, which add yet more challenges to the lives of older people and persons with disabilities living in poverty.

Accessible education

“Non-disabled students get free books, but blind students don’t get free braille books. We need to provide hearing aids, white canes, etc. We need the right equipment and trained teachers for children with disabilities.”

Peer researchers

excluded from school or having a poor educational experience. Teachers need to be trained in disability issues, and environmental, social and other barriers to a quality education removed.

Access to lifelong learning for persons with disabilities and others should be promoted and provided for those for whom education has been previously denied or of low-quality.

Action must be taken to

risk reduction and emergency programmes – including access to shelters. Not doing this leads to increased vulnerability.

The peer researchers who participated in Voices of the Marginalised were clear that commitments to equity and human rights should be backed by campaigns and initiatives aimed at raising awareness of the experiences of people who are ageing and have disabilities, based on an understanding of their lived experiences and including their full participation. They were also clear that full and equal access support to livelihoods programmes is paramount.

Finally, Bangladesh, along with other UN Member States who have yet to do so, need to develop and implement effective national anti-discrimination legislation.

Next steps

The “We can also make change” report from the Voices of the Marginalised project in Bangladesh provided a valuable opportunity to contribute to the body of evidence about what is needed to ensure that the needs and rights of older people and persons with disabilities and mental health issues are included in development initiatives. Next, the Voices project is working with marginalised communities in Africa.

Participatory research processes can communicate powerfully the experiences of people who live on the margins and the Voices project is bringing the perspectives of some of the poorest people in the world into the post-2015 debate. The most important next step is to listen to them and take action.

Awareness campaigns

“We could organise meetings with community elites and religious people to discuss the causes of disability. We could sensitise 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. There should be posters and banners with positive messages in busy places and education centres. We should use the TV to promote a positive attitude."

Peer researchers

References

1  “We can also make change”, the full report of the Voices of the Marginalised project, will be published later this year.
2  These are the recommendations of ADD, Alzheimer’s Disease International, HelpAge International and Sightsavers, and not of the researchers themselves.
6  World Bank (2007).