

Summary

Hear my voice: old age and disability are not a curse

A community-based participatory study gathering the lived experiences of persons with disabilities and older people in Tanzania

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 IFAKARA **HEALTH INSTITUTE**
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HelpAge
International


Sightsavers



Rationale and background

The 2030 Agenda for Sustainable Development, which was adopted in September 2015 by UN Member States, pledges to "leave no one behind" in its implementation.

In order to do so, governments must review their policies and actively engage to commit to the universality, equality, dignity, justice and solidarity expressed in this framework. In order to achieve the 2030 Agenda and the Sustainable Development Goals (SDGs), persons with disabilities and older people must be included. Representing 15 per cent and 11 per cent of the world population respectively, they are amongst the hardest groups to reach, often living in poverty and exclusion. Sightsavers, ADD International, and HelpAge International partnered with Ifakara Health Institute to look into this reality in Tanzania. While persons with disabilities and older people make an invaluable contribution to society, they can be particularly vulnerable when it comes to healthcare, livelihood and access to services.

Our organisations conducted a research study with the following objective in mind:

to provide evidence on the specific nature and experiences of persons with disabilities and older people from their own perspectives in Tanzania, through the lens of social, political, economic and cultural inclusion.

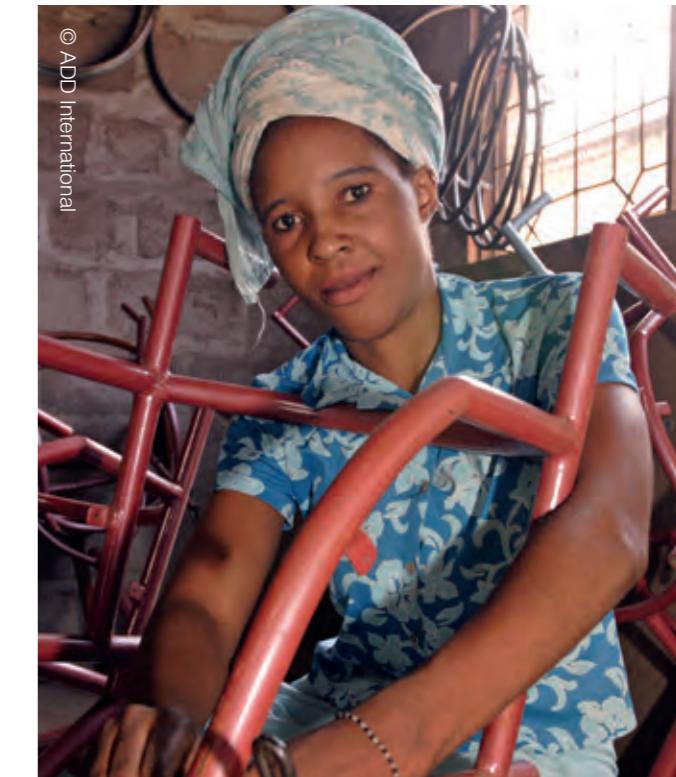
Our aim was to strengthen efforts to provide services for and improve the lives of people living in the rural and urban settings of Nachingwea and Kibaha Urban Municipal Council. These districts were selected because of the presence of active projects with both persons with disabilities and older people by our organisations.

Methodology

The research was based on community-based participatory research (CBPR), which involves respectful collaboration with the community.

CBPR is about shared decision-making and ownership, and members of the community are involved in planning, gathering evidence, analysing the results and sharing what is found. All partners contributed and respected the unique strengths that each person brought. As well as asking specific research questions, the design of this kind of research seeks to break down social injustice and helps everyone to re-think power structures and issues. The overall aim of CBPR is to increase knowledge and understanding of the situation being studied together, to construct meaning together and integrate this with interventions and policy change to improve the quality of life of the community (Greenwood et al, 2016).

Twenty-nine peer researchers (nine persons with disabilities, 10 older people and 10 Tanzanian Non-Governmental Organisation (NGO) members working in these communities) were involved in the study. A total of 106 stories were collected: 36 were collected in the rural settings of Nachingwea, 40 in Kibaha Urban Municipal Council and 30 from NGO staff based in Dar es Salaam. These staff were from Tanzanian NGOs working with older people and persons with disabilities (including physical, visual, hearing, intellectual and psycho-social disabilities, as well as albinism). Forty-four older people aged 60 and above as well as 32 persons with disabilities were interviewed. All types of disabilities were represented in the sample. In terms of gender balance, 57 interviews were conducted with men and 49 with women.



Peer researchers were asked to identify the main issues faced by persons with disabilities and older people in all 106 stories, why they thought the issues occurred and how they were connected. This activity drew on their cultural and contextual experience. Analysis was triangulated by researchers coding 36 interviews that examined all the experiences without assigning importance to them, asking the overall research question: How did participants experience ageing and disability? The findings from this analysis were shared with the community members in person for their consideration and in order to bring the two sets of findings together.

Cover Image: © HelpAge International

Findings

Participants' experience of ageing and disability:

The stories were of participants experiencing ageing, disability, or a combination of both, on an individual, interpersonal (interaction with friends, family and community) and societal level. Many experienced emotional difficulties, such as negative self-perception, stress, various effects on their mental health and, at times, a sense of hopelessness. Moving beyond the experience at an individual level, there were various experiences of ageing and disabilities on an interpersonal level. Stories of both domestic and sexual abuse were collected, as well as concerns over risks of such abuses. A main theme that emerged was that, for persons with disabilities and, to an extent, older people, there was a huge impact on primary and key relationships as a result of individual and community experiences.



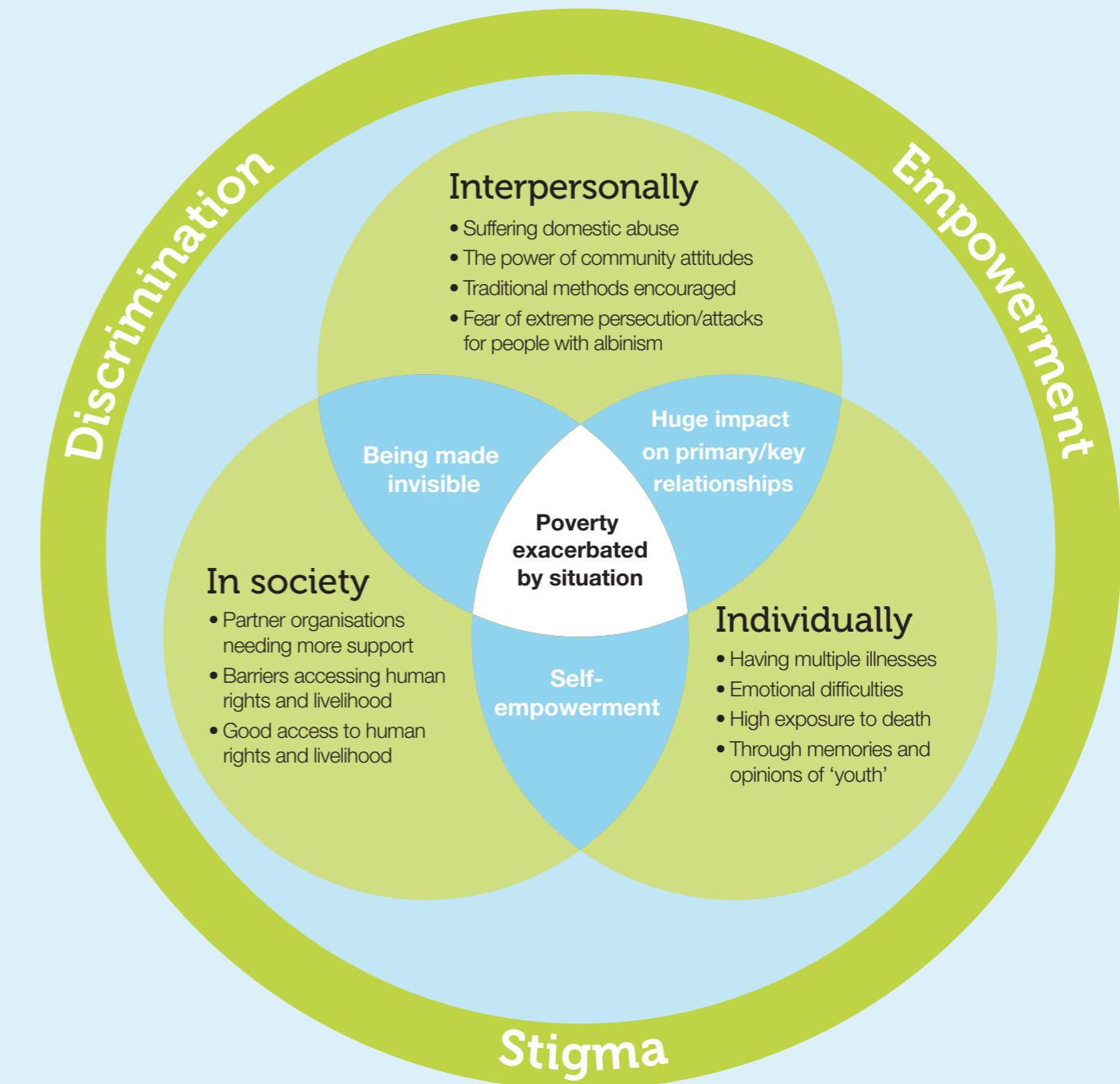
Voices of the marginalised – Tanzania

Tanzania



Research question:

How do participants experience ageing and/or disability?





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Peer researcher suggestions for policy:

Eight priority areas emerged and were chosen by peer researchers for further discussion in groups. They are included in the box below.

Eight priority areas for policy focus and advocacy efforts

1	Access to education and quality learning
2	Access to health services
3	Issues fed back from NGOs
4	Poverty relating to income and dependence
5	Attitudes towards witchcraft and albinism
6	Relationship difficulties and marriage breakdowns
7	Sexual violence and gender issues
8	Poor treatment from family

1. Access to education and quality learning:

While the government has invested much in improving the education sector, participants from this study had experienced a number of challenges, including poor infrastructure of the teaching and learning environment for persons with disabilities. One 18-year-old participant (with a hearing impairment) said: "When I came back from the hospital, I couldn't hear properly. I was bright but started to drop in the class... I left school because I couldn't hear what was being taught so I saw no importance in school."

"Why do you come to school then if you cannot see?"

Discrimination against children with disabilities and limited teacher training have also been reported as obstacles in accessing education. One 25-year-old participant (with a visual impairment) explained: "When I was in primary school, I would tell the teacher that I could not see. I would ask: 'Can you please read for me?' But the teacher would say, 'Why do you come to school then if you cannot see?'."

Older people in both districts wanted to share their lifelong learning within their communities because they felt they had lots to contribute which could be of benefit to everyone.

Ways forward

More broadly, the peer researchers discussed the following ways forward on the issue of access to education and quality learning:

- More teachers should be trained to provide quality inclusive education for children with disabilities.
- Curriculums in primary schools should be flexible and adapt to the needs of diverse learners, so children with disabilities can benefit from quality education.
- Parents of children with disabilities should be sensitised to the importance of taking their children to school to receive an education.
- Older people should be listened to as their life experience is invaluable.

2. Access to health services:

Persons with disabilities and older people in the study cited limited accessibility of health care services. The major issues reported include shortages of medical equipment and supplies at health facilities, poor communication skills among health care providers and costs incurred when seeking care. A 32 year-old participant (with a hearing impairment) explained: "I usually go alone [to the hospital] but I have been experiencing a lot of difficulties because I don't know how to express myself, because health care providers do not understand sign language." One participant from an NGO said: "I remember another sad story in which a pregnant woman who was blind went to give birth at the health facility. She delivered twins but reported that she was given one baby only."

**"If I go to the hospital,
I am not even cared
for unless I have
money to buy drugs"**

.....

An 82-year-old person said: "I have not been paid my pension yet since I retired. I have stopped following the issue because I have written a lot of letters. I am now having a difficult life situation. In general, older people are facing hardship; they are not respected, not cared for, and neglected. If I go to the hospital, I am not even cared for unless I have money to buy drugs. So where can I get the money?"

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issue of access to health services:

- Social welfare officers should make frequent visits to their respective villages to enquire and understand the needs of persons with disabilities and older people.
- Health facility infrastructures should be made accessible to persons with disabilities including training of health care providers on how to interact with persons with disabilities and older people.
- Measures need to be in place so that health facilities can make sure that health staff who abuse or mistreat persons with disabilities and older people are reported and held accountable.





3. Issues fed back from NGOs:

Limited financial resources and dependency on donors were among the challenges faced by NGOs supporting persons with disabilities and older people. For instance, one participant working for a NGO said: "We receive different people seeking assistance. Some people are OK with the advice we provide which can change their lifestyle but others are in need of equipment and other different services which we cannot afford."

"Others are in need of equipment and other different services which we cannot afford"

Participants also mentioned limited funding from the government to support local NGOs working with persons with disabilities and older people, and said that NGOs don't often collaborate. Participants suggested the need to improve the capacity-building of NGOs so they can support marginalised people on how to improve income.

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issues from NGOs:

- NGOs should employ more professionals to help advise persons with disabilities and older people.
- Collaboration among NGOs was suggested to better support persons with disabilities and older people, recognising the intersections between age and disability.
- Participants recommended putting more pressure on the government to allocate enough budget for persons with disabilities and older people.

4. Poverty relating to income and dependence:

Persons with disabilities and older people expressed that there were few sources which they could rely on to generate income. There was also unreliable support from the government and community to these marginalised groups. Those few who were formally employed stated they had received a very small pension which could not sustain their cost of living. A 61-year-old participant explained: "I am old enough but when I look ahead of me, I can't sleep at night. I see I will face difficulties in my old age because I have no savings in the bank and my pension is small. I have pain so I am supposed to get treatment at the referral hospital, I am supposed to go back to Muhimbili National Hospital every three months, but I can't afford it. My life ahead will be a difficult situation (...) That is why I can't sleep at night. The hours pass by until the morning. I am always thinking but I cannot get the answer."

Lack of employment was also cited as a challenge for persons with disabilities, as this participant with visual impairment recalled: "I got my primary education at Soga and was then employed at Kibaha Education Centre in 1979. I worked for approximately twenty years. I started to experience eye problems in late 1996 and my employer paid all my hospital bills at Tumbi hospital but I could not get cured. I was referred to Muhimbili National Hospital where I got operated but from there, I lost my eyesight. I went back to my job but started experiencing problems associated with discrimination and then got made redundant in 1997."

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issue of poverty relating to income and dependence:

- Persons with disabilities and older people should be able to receive support and guidance from local and national authorities so they can (for instance) establish income generating activities as well as be trained in entrepreneurship skills.
- Communities should be supportive of persons with disabilities and older people so they can actively get involved and share their skills, life experience and knowledge.

"I am old enough but when I look ahead of me, I can't sleep at night"

5. Attitudes towards witchcraft and albinism:

Harassment and torture was commonly reported by people with albinism. People with albinism have been killed with their limbs amputated as some people believe this can bring about good fortune, especially during elections, to bring good luck to politicians. Organs of people with albinism have reportedly been used in witchcraft activities as a result of this unfounded belief. A participant from an NGO explained: "Whenever there is an election, the killing of people with albinism increases. This year, the killings were increasing but the community raised their voices and it stopped for a while. If it would not have been the case, we could have experienced a greater number of deaths of people with albinism." Another participant working for an NGO recalled the following: "A woman with albinism (...) was living alone; since there are beliefs associated with good fortune and albinism in our community, she was raped by nine people who wanted to get rich. She got infected with HIV/AIDS. Since she had no alternative, she went on begging and got skin cancer. As she was suffering from skin cancer, she didn't know what to do to survive. As I am talking to you, she keeps on begging while infected with HIV and having skin cancer."

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issue of attitudes towards witchcraft and albinism:

- A national public campaign must be organised to advocate for the rights of people with albinism.
- The government should work with traditional healers and seek the causes of killings of people with albinism.
- Individuals who persecute or kill people with albinism should be prosecuted.
- Communities must be made aware of the medical conditions associated with albinism.

"This year, the killings were increasing but the community raised their voices and it stopped for a while"

6. Relationship difficulties and marriage breakdowns:

Parents of children with disabilities were identified as one of the main reasons for relationship difficulties and marriage breakdowns because they were taking over the role of choosing a fiancée/life partner for their children. Peer researchers said that women with disabilities have been frequently humiliated by being forced to live with men who were not their choice.

"I cannot force him to support me if he has decided not to"

Most women, either because of social norms, their age or their disability, were dependent on their husbands' incomes to run their families. One 35-year-old woman (with a hearing impairment) said: "The man who played an intermediary role in our marriage told the father of my child that according to his religion, he should provide support to the mother and the child for a period of three months. However, my husband refused to provide me with support. He was only supporting his child. It is OK if he has decided that way of not supporting me. I cannot force him to support me if he has decided not to."

Older people felt neglected by their families and communities because they were poor and had no income. They believed that the lifelong experience they had should be used to guide their household and village. Looting of properties belonging to persons with disabilities was also a challenge contributing to family difficulties, because persons with disabilities were perceived as not capable of being responsible of their goods.

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issues of relationship difficulties and marriage breakdowns:

- Participants proposed the establishment of income generating activities and the provision of entrepreneurship skills to families of persons with disabilities and older people in order to strengthen household economies.
- Spouses who leave their families home should meet their duties under national law to continue to provide support.
- Persons with disabilities and parents of children with disabilities should be made aware that all matters related to marriage, family, parenthood and relationships should be decided freely, on an equal basis with others.
- Village chairpersons should have a list of older people and persons with disabilities in their respective localities in order to facilitate coordination and support the household if needed.



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7. Sexual violence and gender issues:

Participants reported that women with disabilities were sexually exploited, threatened or mistreated. It was further explained that peer influence has also contributed to the women with disabilities being harassed in their marriages.

Neglect and abandonment of women with disabilities have also been reported among the families of persons with disabilities and older people. One participant from an NGO talked about the sexual abuse of a woman with disabilities that had been arranged by her parents in order to "fulfil her sexual desire": "We tried to discuss about this issue with the parents but could not reach consensus. Parents said that they had the right to select someone who could take care of their daughter." There were no reports by the older participants of sexual violence or gender issues.

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issue of sexual violence and gender issues:

- Measures should be taken to raise awareness on gender equality and discrimination in communities, including the need to report physical, verbal and sexual abuse to the police.
- Thanks to their participation in this study, peer researchers felt empowered to provide information about sexual education to their respective communities.

8. Poor treatment from family:

Participants have recounted mistreatment. For instance, some parents see a child with disabilities as a burden and therefore, will decide to abandon their child. One 80-year-old woman said: "You should not tell me about the mother of this child [child has a disability]. The mother came here and left her daughter to me when she was very young. Her father is also alive and lives in Dar es Salaam. [The child] calls me mother and not grandmother. She is used to [seeing] me since her childhood, calling me mama, mama... Her mother came to take the daughter to the traditional healer and later left her with me again [after the mother and the traditional healer failed to 'cure' the disability]."

"I stayed at home because they said that a person with hearing impairment is like a patient, that he should not be engaged in any activity"

Other participants explained that they, as older people, have been mistreated by their children. They don't feel supported or cared for. It is a similar reality for a number of persons with disabilities in the study. One participant (with a hearing impairment) said: "I stayed at home because they [family members] said that a person with an hearing impairment is like a patient, that he should not be engaged in any activity. I was just eating and sleeping. They sometimes assigned me with some household tasks. So my life became very difficult..."

Ways forward:

More broadly, the peer researchers discussed the following ways forward on the issue of poor treatment from family:

- The Ministry of Health and Social Welfare office should create awareness among the village leaders in order to reduce stigma and discrimination of persons with disabilities and older people.
- Because of their experience in this study, peer researchers felt they also had a duty to raise awareness about both disability and ageing; and advocate for individual's right to dignity, inclusion, and equality amongst government, village leaders and families.

Conclusion

This study has informed efforts to provide services for and improve the lives of persons with disabilities and older people in Tanzania.

It has also contributed to significant knowledge gaps due to a lack of research in this field and created evidence that can be drawn upon by stakeholders in Tanzania and beyond. The approaches used will help to build strong and inclusive policies which will contribute to informed implementation of the 2030 Agenda as well as the Convention on the Rights of Persons with Disabilities. It has also contributed to building ways of engaging with CBPR methodology in the context of social inclusion and disability, through the study's strengths and weaknesses.

This study serves as a reminder that the situation for persons with disabilities and older people is complex and interconnected, and to serve it best requires listening carefully to their voices and stories, and to the NGOs that support them. They are the voices of the marginalised, but also of the empowered, if we listen well. Local, national and global recommendations continue to gather force from the findings.

Global recommendations

Policymakers must:

- Ratify, implement and monitor the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and support the elaboration of a UN Convention on the Rights of Older Persons (UNCROP).
- Promote the full and equal participation of persons with disabilities and older people in policy formulation at all levels, with systematic processes for meaningful engagement.
- Improve data collection and analysis mechanisms on both disability and ageing to increase knowledge.
- Raise awareness about the experiences of persons with disabilities and older people to counter stigma and discrimination.
- Ensure SDGs-compliant development plans and policies to provide services that are inclusive of persons with disabilities and older people.

Who's behind it?

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 global and national policymaking. It is a collaboration between Sightsavers, HelpAge International, and ADD International with the participation of Ifakara Health Institute to lead the research study in Tanzania as well as the Tanzanian Ministry of Health, Community Development, Gender, Elderly and Children and the Ministry for Labour, Employment, Youth and People with Disability. The study was initially conducted in Bangladesh and then in Tanzania.

The 'ways forward' suggested by the peer researchers will be used as a basis to develop further policy recommendations for advocacy purposes.

Sightsavers

Across the world, persons with disabilities are more likely to experience poverty and social discrimination. Sightsavers is committed to eliminating avoidable blindness and supporting persons with disabilities 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

Ifakara Health Institute (IHI)

IHI is an autonomous, not-for-profit Tanzanian health research organisation registered in Tanzania. The Ifakara Health Institute has an excellent track record for world-class multidisciplinary research to inform public health policy and action. IHI has over 50 years' experience in several programme areas including demand-driven research; data analysis and use; public health; policy analysis and development; monitoring and evaluation and knowledge generation and dissemination. IHI's approach focuses on the effective engagement of key stakeholders throughout the entire research process to ensure uptake.

www.ihi.or.tz

ADD International

ADD International fights for independence, equality and opportunities for persons with disabilities living in poverty. We work in Africa and Asia with persons 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

Tanzanian Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC)

Tanzanian Ministry for Labour, Employment, Youth and People with Disabilities



Further information

To find out more about the Voices of the Marginalised project, and for information about our previous study in Bangladesh, please visit

www.sightsavers.org/voices

or contact

policy@sightsavers.org

Please note:

The images used in this document do not show the participants or interviewees in the Voices of the Marginalised project. We wish to protect their identities.

Title of the summary and full report:

The peer researchers were asked to find the title of the report. Every participant wrote a suggested title in a piece of paper. The proposed titles were then written on the board and read aloud for inclusion purposes. Participants voted for the best title. The following title was then chosen as best to represent the findings: "Old age and disability are not a curse."