Full report

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

September 2016

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HelpAge International

Sightsavers

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Abbreviations

Abreviation	Description
ASBAHT	Association for Spina Bifida and Hydrocephalus in Tanzania
CHAWATA	Chama cha Walemavu Tanzania/Tanzania Association of the Disabled
CBPR	Community-Based Participatory Research
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
CRPD	Convention on the Rights of Persons with Disabilities
DOLASED	Disabled Organisation for Legal Affairs and Social Economic Development
DPOs	Disabled People's Organisations
DSW	District Social Welfare Officer
IDS	Institute of Development Studies
IHI	Ifakara Health Institute
KISUVITA	Kikundi cha Sanaa na Utamaduni cha Viziwi Tanzania (Cultural and Art Group for people with hearing impairment)
MoHSW	Ministry of Health and Social Welfare
MUHAS	Muhimbili University of Health and Allied Sciences
NGO	Non-Governmental Organisations
NIMR	National Institute for Medical Research
REPOA	Policy Research for Development
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
PSORATA	Psoriasis Association of Tanzania
SHIVYAWATA	Tanzania Federation of Disabled People's Organisations
TAS	Tanzania Albinism Society
TASODEB	Tanzania Society for the Deafblind
TLB	Tanzania League for the Blind
TUSPO	Tanzania Users and Survivors of Psychiatry Organisation
WHO	World Health Organisation

Acknowledgements

The authors and contributors of this report would like to thank the many individuals and institutions that have contributed to the study's success. Firstly, the role of Sightsavers in funding this project is highly appreciated. We thank the District Executive Directors (DEDs) from the study sites of Nachingwea, Kibaha, Kinondoni, Ilala and Temeke for allowing this work to be conducted in their areas. We would also like to thank the District Social Welfare Officers (DSWs) for their willingness and cooperation in helping and guiding our research teams.

We would like to thank each division, ward, village and hamlet leader in the study areas, and we highly appreciate the cooperation of everyone who volunteered to be our participants in the villages we visited. We are particularly grateful to the persons with disabilities and older men and women who spent time sharing their stories with us. This work would not have been possible without the immense support and collaboration of Disabled People's Organisations (DPOs) from the study areas and older people's organisations in Dar es Salaam, to whom we extend our sincere appreciation.

We extend enormous thanks to the Sightsavers staff in Dar es Salaam for their support of, and keen interest in, the study – they were fundamental in making it a success. Similarly, we would like to thank ADD International, HelpAge International, CCBRT, SHIVYAWATA, MoHSW, MUHAS and REPOA for being part of the advisory group in this project.

Finally, we would like to thank all the volunteers who worked tirelessly towards realising the study's goals and objectives – they worked under difficult circumstances, and their courage and readiness to consistently provide quality data cannot be compensated with any type of reward or payment.

Summary

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. Governments have to review their policies to actively engage and 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 most marginalised, 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 health care, 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, from a social, political, economic and cultural point of view. 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 respectively. These districts were selected because of the presence of active projects by our organisations involving both persons with disabilities and older people.

Methodology

The research was based on community-based participatory research (CBPR), which involves collaborating respectfully with the community. CBPR is about shared decision-making and ownership, with members of the community 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 to 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.

Findings

Participants' experience of ageing and/or 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. On an individual level, many experienced emotional difficulties, such as negative self-perception, stress, various effects on their mental health and, at times, a sense of hopelessness.

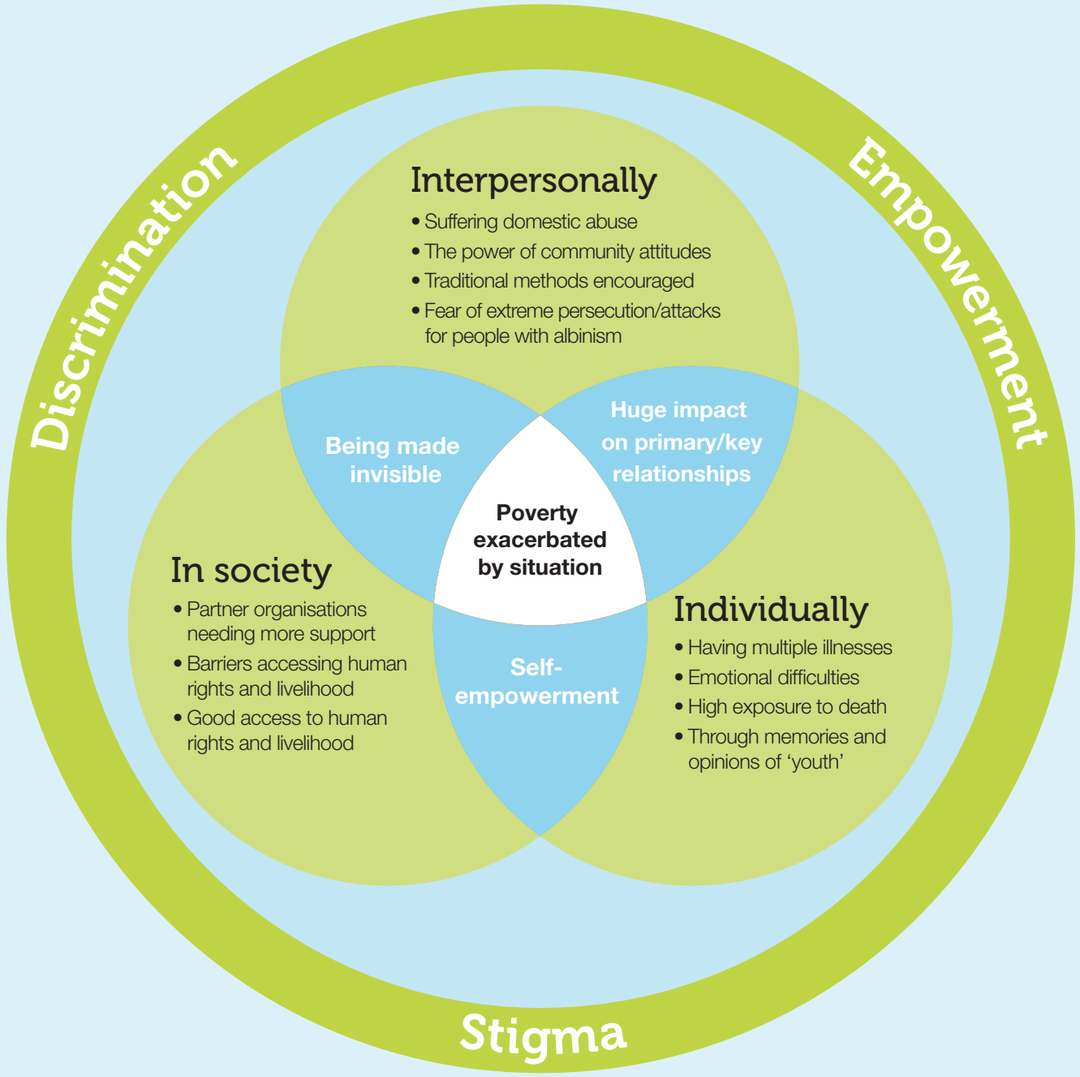
On an interpersonal level, there were various experiences from both groups. Stories of both domestic and sexual abuse were collected, as well as concerns over the risks of such abuse. A main theme that emerged was that, for persons with disabilities and – to an extent – older people, there was a huge impact on primary and key relationships as a result of individual and community experiences. There were many examples of challenging family relationships and marriage breakdowns. A few stories revealed strong and positive marital experiences, despite the overall community experiences.

Zooming out from the interpersonal to a societal level, NGOs working in the field of disability and with older people shared a pressing need for more support of their work at a governmental level, financially and by acknowledging the impact and the issues faced. Persons with disabilities experienced political barriers, discrimination within education, a lack of work opportunities and poor access due to a lack of appropriate transport. Both persons with disabilities and older people had difficulty accessing appropriate health care.

These findings are shown in the diagram below:

Voices of the marginalised – Tanzania

Research question:
How do participants experience ageing and/or disability?



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Peer researcher suggestions for policy:

The peer researchers identified eight priority areas on which to focus policy and advocacy efforts, shown in the box below. These were identified based on their opinions and experiences of the recurring issues raised in all 106 interviews.

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 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 about and understand the needs of persons with disabilities and older people.
- Health facility infrastructures should be made accessible to persons with disabilities, including training 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 care 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 an 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 their incomes.

Ways forward

More broadly, the peer researchers discussed the following ways forward on the issues fed back 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, 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 on, 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 persons with albinism. Persons with albinism have been killed and their limbs amputated as some people believe this can bring about good fortune, especially during elections as a means of bringing good luck to politicians. Organs of persons 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 this had not 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 associating albinism with good fortune 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 continues to beg while being 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 persons with albinism.
- The government should work with traditional healers and seek the causes of the killings of persons with albinism.
- Individuals who persecute or kill persons 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. Most women, either because of social norms, their age or their disability, were dependent on their husbands' incomes to run their families.

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

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 child for a period of three months. However, my husband refused to provide me with support. He supports only his child. It is OK if he has decided to not support 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 their life experience 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 incapable 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 the family 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 "fulfill her sexual desire": "We tried to discuss this issue with the parents, but could not reach a consensus. The 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 of 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 by their own families. 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: “This child’s mother came here and left her daughter with me when she was very young. Her father is alive and lives in Dar es Salaam. The child calls me mother, not grandmother. She has done since her childhood, calling me mama, mama... Her mother came to take the daughter to the traditional healer and later left her with me after the mother and the traditional healer failed to “cure” the child’s 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 a 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 some household tasks. 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 village leaders in order to reduce the 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 filling knowledge gaps due to a lack of research in this area 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 UN 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 may be the voices of the marginalised, but when listened to properly, have the potential to be the voices of the empowered. 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.

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

Background

Estimations by the World Health Organisation (WHO) and World Bank suggest that over one billion people experience some form of disability worldwide, most of them (about 80%) living in developing countries[1]. Globally, persons with disabilities face widespread exclusion. They are routinely excluded from social, economic and political activities and processes, including international development policy, practice and research. Exclusion reinforces the disproportionately high number of people living with disabilities among the poorest of the poor. 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% of gross domestic product (World Health Organisation, 2011).

Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 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).

With one in nine people in the world aged 60 years or over, and a projected increase to one in five by 2050, population ageing is a phenomenon that can no longer be ignored (UNFPA and HelpAge International, 2012). The opportunities that increasing longevity present are endless, as are the contributions that a socially and economically active, secure and healthy ageing population can bring to society. Although the reality of how older people are treated is widely varied across the globe, deteriorating health and mobility, loss of income and social status and effects of ageism manifest in the vast majority of older people. Social exclusion, discrimination, isolation and neglect are more chronic in countries where policies to address the needs and rights of older people have not been well developed (UNFPA and HelpAge International, 2012).

Global ageing has a major influence on disability trends. There is a higher risk of disability at older ages, as well as age-related health problems that can affect sight, hearing, mobility and mental functioning, meaning older people are particularly vulnerable to the poverty-related effects of disability. By 2030, 16.6% of the world’s population will be aged 60 and over, and of those 73% will live in low and middle-income countries (LIMC) (UNESA, 2011). Older people may not consider themselves as having a disability despite enduring difficulties because they consider their level of functioning appropriate for their age.

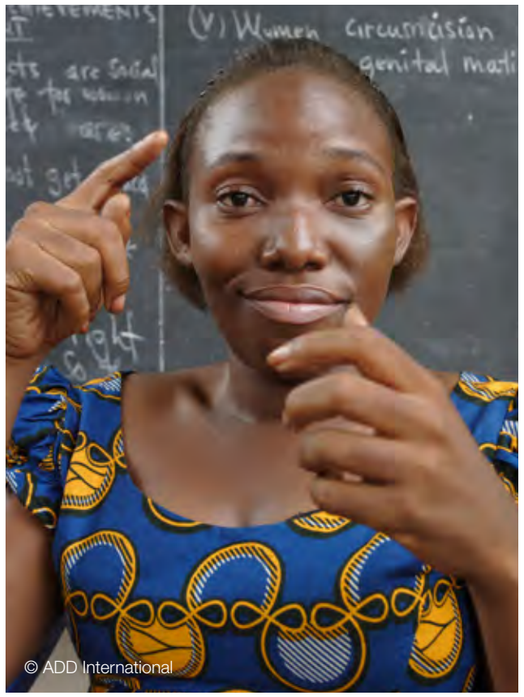
In Tanzania, according to the 2008 National Disability Survey, an estimated 8% of the population is affected by some form of impairment (NBS, 2008). Many persons with disabilities do not have the same opportunities as those without, especially when it comes to accessing health services, education, employment and social protection. According to the Tanzanian Disability Survey, an estimated 20% of persons with disabilities encounter some barriers when accessing health services (NBS, 2008).

Similar to persons with disabilities, older people also experience disproportionate levels of poverty and marginalisation (Burns D. and Oswald K., 2014; United Nations, 2013).The majority of older people, especially in LMIC (including Tanzania), belong to the poorest and most vulnerable groups. Their capacity to meet their own basic needs diminishes as age increases. It should not be presumed that older people in LMIC (including Tanzania) are protected and cared for by their families. For example, a study conducted in Tanzania by HelpAge International (Sebyiga B., 2001) indicated that family care and respect are often undermined as a person grows older. There is, therefore, a call to address this gap created by the collapse of the traditional family support system through a participatory approach that involves older people.

According to the 2012 population and housing census, 5.6% of the Tanzanian population is estimated to be aged 60 years old and above. Based on the UN report, the number of Tanzanians over 60 years of age is expected to triple between 2020 and 2050 (UNFPA and HelpAge International, 2012). As a result, the government is likely to face increasing pressure to design an intervention related to social protection as a strategy to reduce poverty among older people (Mboghoina T. and Osberg L., 2010).

Justification for conducting this study

Ultimately, this research study informs efforts to provide services for and improve the lives of older people and persons with disabilities. It contributes to filling knowledge gaps on older people and persons with disabilities, and is a body of evidence that can be drawn upon by stakeholders in different countries with similar challenges. Wiith the completion of this study, local stakeholders will have greater evidence to ensure that the needs and rights of older people and persons with disabilities are included in the development of interventions. This research directly engaged older people and persons with disabilities because they have the greatest personal knowledge of the issues. The story-based approach helps us to understand how and when the issues raised occur. Though it tells us what is happening, it cannot give us meaningful data on the extent to which this problem occurs.



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Overall objective

The overall objective of this study was to provide evidence on the specific nature and experiences of older people and persons with disabilities from their own perspectives in both rural and urban settings.

Specific Objectives

1. To understand the experiences of social, political and economic inclusion and exclusion of older people and persons with disabilities from their own perspectives in Tanzania.
2. To generate comprehensive knowledge which will guide national and global policymaking, as well as the implementation of development programmes emerging from the 2030 Agenda and the Sustainable Development Goals.
3. To comprehend how older people and persons with disabilities understand inclusion and exclusion within the contexts of their families, communities and broader society.

Methodology

Study Area

The study was undertaken in two districts to represent urban and rural geographical variation: Kibaha Urban Municipal Council and the rural district of Nachingwea District. The districts were purposely selected due to the presence of active projects dealing with both older people and persons with disabilities supported by Sightsavers, HelpAge International and ADD International.

Kibaha District Council was selected from among six districts: Bagamoyo District Council, Kisarawe District Council, Mkuranga District Council, Rufiji District Council and Mafia District Council. Kibaha District is bordered to the north by the Bagamoyo District, to the east by Dar-es-Salaam, to the south by the Kisarawe District and to the west by the Morogoro Region. It is located at latitude -6,7667 (646'0.012"S) and longitude 38,9167 (3855'0.120"E). According to the 2002 Tanzania National Census, the population of the Kibaha Town Council was 128,488 (NBS, 2013).The district has three divisions, 13 wards, 53 street (mtaa) and 25 villages and covers an area of about 1,812 total sq. kms (Regional Commissioner's Office Pwani, 2011/16).

Nachingwea is one of the six districts of the Lindi Region in Tanzania (Regional Commissioner's Office Lindi, 2016). It is located in Southern Tanzania, latitude: -10°30'0" and longitude: 38°19'59.98. The district is bordered to the north by Ruangwa District, to the east by Lindi Rural District, to the southeast by Mtwara Region and to the southwest by Ruvuma Region. According to the 2012 Tanzania National Census, it has a population of 178,464 (NBS, 2013).

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Study design

The approach taken for the study was community-based participatory research (CBPR) (Banks S. and Manners P., 2012). This approach involves a commitment to sharing power and resources, and working towards beneficial outcomes for all participants, especially communities. CBPR, as a partnership approach, aims to equally involve community members, organisational representatives and researchers, who contribute expertise and share decision-making and ownership (Banks S. and Manners P., 2012). It is a research approach which recognises the unique strengths that each person brings. The aim of CBPR is to increase knowledge and understanding of a given phenomenon and integrate the knowledge gained with interventions, policy and social change in order to improve the health and quality of life of community members. Historically, CBPR has been developed in various aspects of public health, but has not been extensively applied to social inclusion. Through developing this methodology in the area of social inclusion, the study will contribute to the expansion of CBPR use.

Advantages of CBPR include (Banks S. and Manners P., 2012):

- Joining partners with diverse expertise to address complex problems
- Improving intervention design and implementation by facilitating participant recruitment
- Increasing the quality and validity of research
- Enhancing the relevance and use of data
- Increasing trust and bridging cultural gaps between partners (including participants)
- Providing resources for the communities involved
- Benefiting communities and researchers alike through the knowledge gained and actions taken
- The potential to translate research findings to guide the development of further interventions and policy change

Ideally, community members would actively participate in the conception and design of a project, as well as data collection, analysis, interpretation and conclusion. Ifakara Health Institute in Dar es Salaam partnered with community members with disabilities, older people and NGOs from the research districts and engaged them as peer researchers in data collection, analysis and how to act on findings. However, the conception and design was based on the pilot study in Bangladesh and so community members in Tanzania were not part of this process.

The project aimed for a reciprocal appreciation of each partner's knowledge and skills at each stage. Rather than creating knowledge for knowledge's sake, the focus was on incorporating research and reflection in order to affect change in the project districts. The project itself did not fund these changes based on the findings, but there are plans for global and national policy and advocacy work, both within Sightsavers, HelpAge International and ADD International, and by partners based in Tanzania.

Sample size and sampling

We recruited 29 peer researchers in order to generate a range of stories from the experiences of both groups of older people and persons with disabilities. Key informants from Tanzanian Non-Governmental Organisations (NGOs) working with these two marginalised groups were also among the participants identified for story collection with regards to their experiences in dealing with the target group.

Table 1 below shows descriptions of the overall sample size of the study. The planned numbers of stories was 94, however we ended up collecting 106 stories. This was due to the additional peer researchers who were maintained from the reserve list.

Type of peer researcher	Number of peer researchers	Number of stories to be collected per person	Total number of stories
Community peer researchers	19	4	76
NGO peer researchers	10	3	30
Total	**29**	**N/A**	**106**

Table 1: Sample size in Kibaha and Nachingwea

Selection criteria for community peer researchers and NGO staff

Community peer researchers

Recruitment: Peer researchers with disabilities were nominated by NGO staff from the steering committee and the advisory group[1] as appropriate for the role of peer researcher. The research team from Ifakara Health Institute met with the proposed individuals and judged whether they were suitable for the community peer researcher roles.

In brief, 19 community peer researchers were recruited: 10 from Kibaha and 9 from Nachingwea. The criteria selection was based on gender, age, disability, socio-economic characteristics and understanding.

Disability, Age and Gender: Nine of the peer researchers were adults (above 18 years old) and had different types of disabilities (visual, mobility, hearing, albinism). Persons with psycho-social disabilities and intellectual disabilities did not participate as community peer researchers, but as participants. This was agreed during the advisory group meeting as members felt they were ill-equipped to offer the appropriate support to persons with psycho-social disabilities and intellectual disabilities during workshops1. Gender equality was also among the criteria for the recruitment of the peer researchers. Ten peer researchers were older persons (as defined in Tanzania, this is age 60 or over).

Socio-Economic Characteristics: The peer researchers were selected from a range of localities in the study areas in order to achieve an accurate representation of community diversity in terms of ethnicity and poverty. Care was taken to select people from across the community, including people who may be excluded due to different factors, and not only people who have existing leadership roles in the community.

Understanding: During the selection process, it was imperative that community peer researchers should be selected based on good listening skills, empathy and full and active participation in the peer research workshops. All peer researchers were asked to participate in the study and to be available for the whole duration of the research. All the peer researchers had a clear understanding of the meaning of 'informed consent'.

Adaptation and Support: Support was provided to enable people with a range of disabilities, and from a range of ages, to participate fully and safely in the research. Appropriate adaptations were made and, in some cases, adjustments were requested to enable full participation. This was also common in the training venues and accommodation during any field work.

NGO staff

Ten staff from Tanzanian NGOs working with older people and persons with disabilities (physical, visual, hearing, intellectual, albinism) were selected, observing gender balance. It was imperative that NGOs participating in the research should be those working at community level, among diverse communities and located in different parts of the country. Likewise, a representative from the social welfare department of the Tanzanian Ministry of Health and Social Welfare (MoHSW) working with older people and persons with disabilities was invited to attend the workshops and become a peer researcher.

1. For more information about the steering committee and the advisory group, go to page 28

Visiting the recruited peer researchers

The recruited peer researchers were visited by the research team (IHI staff) in their respective districts in order to gauge whether they met the criteria identified for this study and the research activity. The team also used this opportunity to explain to peer researchers the purpose of the study and what was required of them, as well as briefing them about the upcoming training in Dar es Salaam. The visit also provided an opportunity for peer researchers to ask questions related to the project.

Data processing and management

Data analysis

Stories collected by the peer researchers were recorded (with the participants' permission) using digital audio recorders (Sony # ICD – PX312), then transcribed verbatim by a trained transcriptionist. In order to maintain anonymity, all personal identifiers were not present at the point of transcribing. The first stage of data analysis was conducted locally, with consultation from the Institute of Development Studies (IDS-UK) during a three-day analysis workshop to discuss interpretations of the data. This was done in collaboration with all the peer researchers of the study for a shared understanding of key findings.

The peer researchers were asked to identify the important issues in the 106 stories, why they thought they happened and how they were connected. This activity drew on socio-cultural, context-specific experiences of these community members. Alongside this, research staff at Sightsavers' UK office coded 36 interviews (just over a third of the total) driven by the research question: How did participants experience ageing and disability? The findings from this second stage analysis were later shared with the community members in person for their feedback and validation (see annexe 5 "report validation workshop" page 72). The coded analysis considered all the experiences within a story, without assigning importance to them. The aim was not simply to use researchers to code this data, but to use the activity to invite policy, advocacy, programme and evaluation team members to learn the process of qualitative coding, and be immersed in the stories. The analysis was a three-tier coding process as identified in Table 2:

Level of coding	Explanation
Open coding	The process of breaking down, examining, comparing and conceptualising data
Axial coding	Making connections between categories
Selective coding	Selecting the core theme by systematically comparing it to other categories. A core one is the central issue into which all other groupings are integrated

Table 2: A three-tier coding process

Data quality and management

All research activities were conducted in accordance with internationally recognised standards. Translated materials were reviewed by fluent local partners to ensure the report's validity, and report validation workshops were conducted in the respective study districts. Data was securely stored (with independent backup) at IHI and later shared with Sightsavers. Researchers also maintained field notes to supplement the data. All files were zipped and saved in both password-protected folders and computers.

Ethical review

Ethical approval was sought from the Ethical Committee of Ifakara Health Institute and the Medical Research Coordinating Committee of the National Institute of Medical Research (NIMR/HQ/R8a/Vol. 1X/1965). The study team ensured that adequate information about the project was available at national, regional and district health authorities. Meetings of the district officials from each of the study areas were convened in order to explain the nature of the project to them, and individual written informed consent was sought from the study participants.

The study complied with the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Association W.M., 2000, Vallotton M., 2010). Each participant was given an information sheet about the study in Swahili, explaining why the research was being carried out, by whom, and what it involved for both participants and researchers. Participants were then asked if they had any questions and whether they agreed to take part in the study. The confidentiality of all participants was assured. The study involved low risk to participants, and any participant with an acute illness or social needs was referred to a health facility or social welfare office.

Ethical principles

The study followed the ethical principles recommended for CBPR by the Centre for Social Justice and Community Action and National Co-ordinating Centre for Public Engagement (CSJCA & NCCPE 2012):

- Mutual respect – for example, being prepared to listen to the voices of others, accepting that there are diverse perspectives;
- Equality and inclusion – for example, seeking actively to include people whose voices are often ignored, challenging discriminatory attitudes and behaviours and ensuring information, venues and formats for meetings are accessible;
- Democratic participation – for example, acknowledging and discussing differences in the status and power of research participants, working towards sharing power more equally, using language everyone can understand;
- Active learning – for example, ensuring time to identify and reflect on learning and sharing responsibility for interpreting the research findings and their implications for practice;
- Making a difference – for example, debating what counts as positive change and building it in as a goal;
- Collective action – for example, agreed visions and goals that meet partners' differing needs for the research and for how to share knowledge and power more equitably;
- Personal integrity – for example, accurate and honest analysis and reporting of research, being open to challenge and change and prepared to work with conflict.

The research team ensured mutual respect, equality and inclusion and democratic participation while working with the peer researchers. Active learning took place through the designing, analysis and validation of the final report. Through analysis and validation workshops, the team engaged in debate about what counts as 'positive change' and what is 'sustainable'. It committed to working together to achieve change through shared vision and conflicting interests. Collaboratively, the team aimed for accurate and honest analysis and reporting, whilst always being open to challenge.

The steering committee and the advisory group

Prior to data collection, there was a steering committee and advisory group which had the following responsibilities: to advise the research team about the project, research design, methods, site selection and peer researchers selection, background materials and useful contacts and comments on the report and participation during dissemination. The steering committee was formed by four collaborating institutions: Ifakara Health Institute (the leading research team), Sightsavers, HelpAge International and ADD International. The advisory group was formed by eight organisations working with older people and persons with disabilities including the Ministry of Health and Social Welfare (MoHSW). It included members from Disabled People's Organisations (DPOs), Comprehensive Community Based Rehabilitation in Tanzania (CCBRT), Kisuvita Organisation, Tanzania League for the Blind (TLB) and a mental health specialist from Muhimbili National Hospital and Muhimbili University of Health and Allied Sciences (MUHAS).

Steering committee meeting

The steering committee was set to have two meetings, one during the planning and the second before the dissemination of the research findings. The first meeting took place on 16th April 2015 at Sightsavers' office in Tanzania, while the second will be conducted prior to the dissemination of the report. Five participants attended the first meeting: two from IHI, and one from Sightsavers, ADD International and HelpAge International respectively. Among other things, the meeting discussed the background, objectives and methodology of the proposal, as well as ways of improving the document. During the discussion, members further proposed the recruitment of two sign language interpreters to facilitate the upcoming peer researcher training workshop. During the meeting, it was also suggested that a mental and intellectual health specialist be invited to the advisory group to advise whether or not to include persons with psycho-social disabilities and persons with intellectual disabilities.

Advisory group meeting

Like the steering committee, the advisory group was also set to have two meetings: one during the planning phase and the second before dissemination of the research findings. The first meeting took place on the 22nd April 2015 at HelpAge conference hall in Dar es Salaam, while the second meeting will be conducted after the publication of this report.

The meeting was attended by representatives from IHI, SHAVYAWATA, CCBRT, KISUVITA, ADD International, TLB, HelpAge International, MNH/MUHAS (mental health specialist), MoSW/Social Welfare Department and a sign language interpreter. The IHI researchers presented the background of the study, its objectives, methodology, study areas and the selection criteria of the peer researchers. Like the steering committee, the advisory group made some important input regarding site-selection justification, and the inclusion or exclusion of persons with psycho-social disabilties.

The mental health specialist expressed his view that involving persons with psycho-social disabilities and intellectual disabilities, as both peer researchers and study participants, would be manageable within the research. He highlighted that peer researchers with psycho-social disabilities or intellectual disabilities would require and should receive extra support. However, individuals with psycho-social disabilities and intellectual disabilities were not used as peer researchers because the advisory group felt it did not have the skills to recruit and support meaningfully representative of these two groups. This is an important finding of the study in itself and requires a deeper look as to why it was deemed difficult to provide the support required to individuals with psycho-social disabilities or intellectual disabilities.

Definition of terms

Disability

Throughout this document, the term "persons with disabilities" is used as terminology adopted by the CRPD and used internationally (Freeman et al., 2015). Disability is a broad term used to describe the barriers that individuals face as a result of impairment or of limitations to their activities, or an inability to participate fully in society (Burns, 2014). These barriers generally fall into three categories:

- Environmental eg inaccessible buildings and services
- Attitudinal eg stereotyping, discrimination and prejudice
- Organisational eg inflexible policies, practices and procedures.

This study therefore adopted a diverse understanding of disability encompassing, for example, someone born with a congenital condition such as cerebral palsy, or a person who has damaged their leg in an accident, or someone with schizophrenia, or an older person with dementia, or someone with a chronic illness (Burns D. and Oswald K,, 2014).

Old age

In developing countries – Tanzania in particular – ageing is not defined using the same common terms as in developed countries as it encompasses the retirement age (Ngallaba S.E. et al., 2016). For the purpose of the analysis, ageing in the Tanzanian context may be defined as follows:

"Ageing is a biological process which has its own dynamic, largely beyond human control. The age of 60 years and above, roughly equivalent to retirement age in Tanzania, is said to be the beginning of old age" (United Republic of Tanzania, 2003).

Peer researchers

Peer research is a form of participatory research. Peer researchers are people rooted within particular constituencies or communities who are supported as they generate research with their peers. The community peer researchers in Kibaha were proposed by the local NGOs working in the grassroots networks, including HelpAge International and ADD International, while those from Nachingwea were proposed by the Nachingwea District Disability Organisation. A breakdown of the community peer researchers recruited in this study is shown in table 3 (over the page). Two groups of peer researchers were involved in conducting the study:

1. Community peer researchers

These older people and persons with disabilities were from each of the two sites selected for the research: one urban slum and one rural area. The selection criteria for community peer researchers was their disability, age, interests and gender. We were ideally looking for 16 community peer researchers, but ended up recruiting 19 (explained on page 21).

2. NGO peer researchers

These comprised staff from Tanzanian NGOs who worked with older people and persons with disabilities. The criteria for their selection was their gender and experience of poverty and/or exclusion. In addition, selection criteria included organisation type and geographical location, to ensure a good geographical spread and representation of diverse local NGOs. People with experience of participatory techniques and with strong peer networks were given extra consideration during the recruitment process.

We recruited 10 NGO peer researchers working in Tanzania. The NGO peer researchers were represented by TUSPO, TLB, TAS, PSORATA, ASBAHT, TASODEB, SHIVYAWATA, CHAWATA, KISUVITA and DOLASED. The NGOs who were invited to the training workshop were proposed during the advisory group meeting with the support of SHIVYAWATA.

	Districts					
	Nachingwea			Kibaha		
Sex	Older persons	Persons with disabilities	Total	Older persons	Persons with disabilities	Total
Male	2	3	**5**	3	2	**5**
Female	2	2	**4**	3	2	**5**
Total	**4**	**5**	**9**	**6**	**4**	**10**

Table 3: Community Peer Researchers

Communication among the research team during the fieldwork

During the fieldwork, all mobile numbers of the peer researchers, volunteers and the research team leaders were printed and distributed to everyone. This was important to facilitate communication not only among the peer researchers themselves, but also with the IHI staff.

Research design and planning workshop

A research design and planning workshop was conducted on 12-15th May 2015 at Tanzania Episcopal Conference Centre. A total of 29 peer researchers attended the training. Peer researchers established the rules that would guide them during the workshop. Participants were also asked to mention what they expected from the training.

After explaining the objectives of the research, the principles of participatory research were introduced. The training session was interactive, with peer researchers contributing to the discussion under the guidance of the facilitators. In most of the sessions, the peer researchers were divided into small groups. The NGO peer researchers formed two groups of five individuals and the community peer researchers formed three or four groups of five to six individuals. Among other things, peer researchers were trained on story (data) collection, ethics, informed consent process, how to gather rich data and documentation of a story. A note-taker recorded and documented all stories collected. A senior researcher and a project manager from IHI took part as key trainers during the four days of training. For more details, see annexes 1 to 4 on pages 66-71 covering interview guides, information sheet and consent form.

Soon after the training, pre-testing of the story collection was conducted in Mkuranga district. Each peer researcher collected at least one story. During the feedback session, each team reviewed the story collected and the feedback was then shared with the whole team as a means of improving the ways of gathering rich data through skilled story collection during the actual fieldwork. The pre-testing exercise was very useful in several ways and included: testing the flow and relevance of the prompt questions, wording and terminologies; testing subject understanding by the community peer researchers; testing logistical issues and estimating the duration for the actual fieldwork.

The prompt questions agreed for community peer research were:

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

The prompt questions agreed for NGO peer research were:

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

Mid-workshops: Kibaha, Nachingwea and Dar es Salaam

Mid-workshops were conducted in Kibaha, Nachingwea and Dar es Salaam and were facilitated by the IHI research team. The objective of these workshops was to assess if the peer researchers were on the right track in terms of identifying the right participants, the mode of asking the guide questions and good probing, and maintaining the quality of stories collected. Except for the NGO peer researchers who collected stories for one day, all community peer researchers collected two stories over two consecutive days before they attended the mid-workshops.

The mid-workshops were helpful in different aspects. They reminded the teams about what exactly they were supposed to do. The review of the collected stories was done through the peer researchers' feedback, and recorded stories were played back in a computer so that peer researchers could hear their stories and provide comments. These workshops were very useful to both peer researchers and the research team, with the input received helping to improve the detail and relevance of stories collected.

Stories

One-hundred and six stories were collected in total as shown in Table 4 below.

	Nachingwea			Kibaha			Dar es Salaam
Sex	Older people	Persons with disabilities	**Total**	Older people	Persons with disabilities	**Total**	NGOs
Male	16	8	**24**	14	10	**24**	21
Female	8	4	**12**	10	6	**16**	9
Total	**24**	**12**	**36**	**24**	**16**	**40**	**30**

Table 4: Number of stories collected (106 in total)

A total of 48 participants were above 60 years of age, 13 of them with a disability (see Table 5). A total of 28 participants had a disability who were under 60 years of age. Thirty participants were working either in the field of disability, ageing or both as shown in Table 6.

S/No	Participants	Number
1	Older people also with disabilities	13
2	Older people without disabilities	35
	Total	**48**

Table 5: Older participants and disability

S/No	Field of work	Number
1	Persons with disabilities	24
2	Older people	3
3	Social Welfare (both persons with disabilities and older people)	3
	Total	**30**

Table 6: Participating NGOs/Institutions

Research analysis workshop

In September 2015, a three-day research analysis workshop took place in Bagamoyo. The community and NGO group worked together to analyse the 106 collected stories. The selected pairs were asked to read seven stories together and identify each story's causes and consequences. Each pair of peer researchers was grouped to include participants from both urban and rural areas. The participants were requested to write the various issues within the story on the back of a piece of paper with a coloured sticker for reference purposes. The analysis processes started by identifying the key issues as well as telling what the story was about. In addition, peer researchers were asked to document what was interesting – and what was difficult – during the analysis process.

The peer researchers were asked to prepare their coloured stickers ready for the clustering exercises on the third day of the analysis workshop. The facilitator assured the peer researchers that issues put on the board into emerging categories could later be shifted to another category or be placed in more than one. The clustering exercise continued until more than twenty categories were clustered on the board as emerging themes of the stories. From these, priority areas were identified for policy focus and advocacy efforts going forward. In identifying the priority areas, the peer researchers identified what they considered important in the stories and why, the key messages and how events were linkedin terms of causes and consequences.

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Findings

Peer researchers' chosen priority areas on which to focus policy and advocacy efforts

After having gone through the clustering exercise, eight issues emerged as "priority areas" and were picked for further discussion in groups. The teams were divided into three separate groups: one with NGO peer researchers and two others made of community peer researchers. Each team discussed four issues separately and further connected the issues in the big map. It was important to describe the issues carefully so that people with visual impairment could easily understand. The ordering of the below eight issues is simply the authors' preference.

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

Table 7: Main priority areas identified by peer researchers within the 106 stories

1. Access to education and quality learning

Participants believed that the government has not invested much in this sector, especially for persons with disabilities. Teachers are not adequately trained to teach children with disabilities, while school infrastructures are not accessible. The participants further noted that the community does not provide enough support to persons with disabilities. Likewise, families of children with disabilities have not paid serious attention to issues related to education; for example: most children with disabilities are left at home without being sent to school. Cost of living and illness were among the reasons for children with disabilities to quit college or school. Despite the free education policy for children with disabilities, parents still pay school fees like other students without disabilities. The following typical statements relating to the challenges faced were recorded:

"Services that were offered by the government in the past are not currently provided. For example, the government helped purchase the bicycles and other equipment, and provided sponsorship to students with disabilities in government schools and colleges. Currently things are different; even if the opportunity exists to attend college, the cost of living is high, there is no free food or exercise books so one cannot afford it. So, the trend of persons with disabilities who go to school or college has gone down. Children with disabilities remain at home as their family members cannot afford to pay school fees."

Person with physical disability,
54 years, Kibaha District

"When I was discharged from the dispensary, I lost my hearing. I continued staying with my aunt at home while using drugs prescribed at the hospital and felt better. 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."

Person with hearing impairment,
18 years, Nachingwea District

Discrimination from teachers and fellow students was also among the reasons for children with disabilities to quit school:

"When I attended school, I was humiliated by teachers and decided to quit. I was the only person with albinism in the class. For example, the teacher would tell me that I had to sit at the front because I had a visual problem and couldn't see well, but in fact I was already in the front seat."

Person with albinism,
19 years, Nachingwea District

"While in school, I got harassed. It started when I was in class two and was mainly from fellow girls."

Person with physical disability,
32 years, Nachingwea District

"My mother asked me to sit at the front of the class, but it didn't help. She decided to take me to a college to learn mechanics and I later went to VETA[2] but my main problem was ear impairment. I was doing excellently during practical sessions, but not in the classroom. I lost hope as there was no sign language translator, and I went back home."

Person with hearing impairment,
33 years, Kibaha District

"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 if you cannot see?" Besides, there were no user-friendly learning materials."

Person who is blind,
25 years, Kibaha District

"When I reported at the college, I was advised to change my course due to my disability. I went for the environmental engineering course offered at the Ardhi University (UCLAS) but when I started, I was again advised to change the course just because I was a person with disability. I went back to the main campus at the University of Dar es Salaam, but when I went there, time had already passed (about one month) since the studies had started. I was informed that since other students had already attended classes and been awarded marks in some of their coursework, it was not possible for me to join classes. I was therefore forced to postpone my studies."

Person with physical disability,
41 years, Nachingwea District

[2] VETA – Vocational Education and Training Authority

2. Access to health services

A number of issues arose during discussions on health-related matters facing older people and persons with disabilities. For example, participants noted that their extended families (a family group which consists of parents, children and other relatives living together or in close contact, Dictionary of Unfamiliar Words 2008) was more supportive in caring for persons with disabilities and older people compared to a nuclear family with no relatives to take care of them. However, modern economics has changed this, with many participants mentioning that the traditional system of relying on family was more beneficial to older people and people with disabilities.

Participants also mentioned that a lack of medical equipment and supplies at health facilities was among the major challenges faced by the health care system in Tanzania. Although people with National Health Insurance (NHI) cards (the NHIF was established by the act of the Parliament no. 8 of 1999 and began its operations in 2001, Zitha M., 2012. It was intended to cover public servants but recently, there have been provisions which allow private membership, Yeo R. and Moore K., 2003) can pre-pay for their services, a shortage of medicines was reported to be among the main challenges facing persons with disabilities in health facilities. For example, persons with disabilities may travel miles to their nearest health facility but upon getting there, may not be treated because the clinic is not accessible to support persons with disabilities. This is explained opposite:

"There are challenges related to health issues. Firstly, there is no special place for people with disabilities to see the doctor or take the prescribed drugs. Therefore, people with disabilities stay in the queue just like anybody else who has no disability. Sometimes people with disabilities miss the service they went to the health facility for – eg medicine stocks running out in public health facilities. This is a big challenge because we need assistance."

Person who is blind,
50 years, Kibaha District

Poor communication skills among health care providers are also mentioned in many stories as recurrent barriers in most health facilities. Discussion with participants from the NGO group reported that health care providers have not been trained in sign language, for instance, to communicate with people who are deaf or hard of hearing.

"I have experienced different challenges in my life. Firstly, I have been discriminated against by some of my family members, and I do not get good cooperation from them. If I become sick, my relatives do not take me to the hospital. I usually go alone 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."

Person with hearing impairment,
32 years, Kibaha District

"With regards to health services, there are some challenges relating to communication barriers with health care providers. For example, the medical personnel don't understand what I'm saying."

Person with hearing impairment,
27 years, Kibaha

The study participants acknowledged that because the cost of living, including the price of health care, has gone up, family support to older people and persons with disabilities has gone down. It was also reported during the discussion that there is a circular from the Ministry of Health which states that health services for older people and persons with disabilities are free of charge. However, participants reported that in some regions, this circular has never been received. Participants from the NGO group said that further advocacy is needed to ensure that the government implements the circular so that older people and persons with disabilities can benefit from free health services.

"Older people are not well treated. The government says that treatment for older people, children and pregnant women is free of charge, but this is not the case. If you go to the hospital, the doctor tells you that your prescribed drugs are not available but can be purchased in the drug shop. This is unjust and it pains me."

Older person,
70 years, Kibaha District

"I have not been paid my pension 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?"

Older person,
82 years, Nachingwea District

"There was a time when I experienced some coughing and I reported it to the village leaders. I was given a letter to get free treatment at the hospital. I used this service for a little while but they (the hospital staff) took away the letter and told me that I was not entitled to get free treatment for the type of illness I had. From now on, I must go with cash to get treatment. If I do not have money, I just stay at home and buy some Panadol."

Older person,
70 years, Nachingwea District

Furthermore, peer researchers said that the community should also help the government to take care of older people and persons with disabilities. Another proposed solution was to train health care providers to provide better care to these particular groups.

"Some infrastructures such as [hospital] beds are not suitable for people with disabilities. Moreover, it will also depend whether the nurses are humane, if they will help you get into the bed. 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."

Participant from NGO,
46 years, Dar es Salaam

In addition, participants acknowledged that although there was a very good policy (Aldersey, H.M. &Turnbull, H.R., 2011) in place dealing with issues related to the rights of older people and persons with disabilities in Tanzania, it has not been implemented. For example, older people are exempt based on policy documents but are still incurring some medical expenses related to the purchases of drugs.

3. Issues fed back from NGOs

Limited financial resource was reported as one of the main challenges by participants. NGOs' budgets depend mostly on donor support and limited funding from the government. Some NGOs reported to not even have a permanent office for their activities, while subsidies from the government that were given in the past have now stopped. Previously, NGOs used to get financial assistance from the government. The government's budget to NGOs was about 15 million Tanzanian shillings (approx. GBP£4900), which was an average of 1.5 million for every organisation (approx. GBP£488). Despite the fact that funding was still not enough, the support was later stopped for unknown reasons. Participants said that they have started some initiatives to enable the government to resume funding NGOs that serve people with disabilities. Although the amount given is helpful, it is still not enough to cover these NGOs' budgets. For example, some organisations like CHAWATA have many more members compared to the Tanzania Albino Society (TAS), but were receiving equal funding. This is impractical as some DPOs have many more members and a broader coverage than others. Besides, in various DPOs, some members are representatives of persons with disabilities. They don't have a disability themselves and do not effectively and realistically represent persons with disabilities. The following typical statements highlighting NGO issues were recorded:

"There was a person with vision impairment who was living with his relatives in Mjimwema Kigamboni. It is unfortunate that he didn't attend school. His relatives were not being fair – he was living in a small room with a hole he used as a toilet. He was given food in the same room. As an NGO, we received this information and went to see him. He was not even permitted to go outside or wash his body, and was sleeping on the ground. He never changed his clothes. We met his relatives whom he was living with. Then when we reported this story to the public in 2008, our project sponsor wanted us to visit the house again with people from the media but when we went to the household, his relatives said he has been taken to his relatives in Tanga region."

Participant from NGO,
48 years, Dar es Salaam

"This organisation is meant to help older people who fought in World War II. But in fact, nothing is being given to them as they are waiting for rent to be collected from the buildings left by the British colonialists. This has led to unavoidable confrontation among the members."

Participant from NGO,
62 years, Dar es Salaam

"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."

Participant from NGO,
48 years, Dar es Salaam

"For most of those who want to set up a business, we do not have enough capital to support them. We have limited financial resources. I also worry about what happens next for the young boys with disabilities who have completed school. We had been working with one of the directors of training at VETA who allocates 10 posts for students with disabilities every year, but he has been relocated. Ten posts wasn't much, but it was helpful."

Participant from NGO,
43 years, Dar es Salaam

The above stories reveal how much NGOs value their work with other stakeholders, however their efforts to provide capital and equipment to positively change the lives of persons with disabilities and older people is frequently hindered by limited financial backup. For example, TLB has been supporting schools for people with visual impairment in different ways, as explained below:

"A lack of learning materials for students with disabilities has been a main challenge. There have been delays in purchasing and distributing this equipment to the special schools. This has made the learning environment difficult for the students. In this case, TLB decided to look for other development partners to rescue the situation. The association contracted the Kilimanjaro Blind Trust Association to supply special papers used by persons with eye impairment for about two years. In that contract, we had also requested the maintenance of the Perkins braillers and the purchase of new machines for people with vision impairment."

Participant from NGO,
44 years, Dar es Salaam

4. Poverty relating to income and dependence

Older people and persons with disabilities face a number of challenges related to poverty, income and dependence, with participants from both groups reporting to have little income. During the discussion, older people complained about limited support from the government and the community. For those few older people who were formally employed, they reported to have received very little amount of pension which could not substantially sustain their cost of living. For example, the amount received was at times also used to take care of their children and grandchildren. Lack of employment was also mentioned as a challenge for persons with disabilities. The following story extracts summarise key challenges related to poverty, income and dependence.

"With my old age, I am paid a pension of 50,000/= Tshs per month (approx. GBP£16). However, the money is just paid once – 150,000/= (approx. GBP£48) every three months. I have dependants – six children, a wife and grandchildren. Other children have become adults and are independent and live on their own. Three months without money? I have to get a loan somewhere so that I can pay it back when I receive my pension."

Older person,
70 years, Nachingwea District

"People with disabilities are experiencing problems. This is because we are not employed. We do not have enough income, yet we have children depending on us."

Person who is blind,
50 years, Kibaha District

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During the discussion, some of the peer researchers said that being older was the main reason for living a poor life in both the urban and rural districts. There were little opportunities available related to income-generating activities for older people.

"I am old, 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 difficult – I can go outside the house now but in the months ahead, I will not manage. This situation will even hinder me from getting my daily bread. 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."

Older person,
61 years old, Nachingwea

"Another challenge is the availability of employment opportunities. Nowadays, we hear songs about lack of employment for the youth. We have asked the Ministry to provide soft loans to the unemployed youths. We have also established SACCOS (a local fund) among our members so that they can get loans from our savings. We have also asked other stakeholders such as the Foundation for Civil Society to include components on income-generating schemes in their projects to help older people and people with disabilities."

Participant from NGO,
44 years, Dar es Salaam

"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 was operated on, 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."

Person who is blind,
50 years, Kibaha District

During the discussion with peer researchers, they reported that some people pretend to live with a disability to take advantage of the system. This could be due to poor understanding, and possibly poor coordination of the community support for persons with disabilities. The following quote illustrates this issue:

"I remember there was a case of a young man who pretended to be deaf and ended up raising two million shillings (approx. GBP£650). He went to the office of the district commissioner and said that he was studying in Washington, America and had just come to Tanzania for a holiday. He claimed he was unable to go back to college in Washington due to a lack of money and so he needed financial support. He added that his family was poor. The district commissioner agreed to raise funds, and all heads of department and workers in the district council were asked to contribute. The exercise went well – we were able to raise enough funds, and the young man was given the money so that he could go back to the college in Washington. However, after two days, the district commissioner met the young man (who had claimed to be deaf) in a bar drinking and talking to someone."

Person with physical disability,
48 years, Kibaha District

There was another case whereby a man with disabilities went to seek a job for his wife so that they could raise their household income. His wife was successfully employed but was later married to someone else. Peer researchers have reported that the majority of older people and persons with disabilities feel they are less valued because they receive little income. For example, there was an older man in Nachingwea District who asked local government officials to provide him with a platform so that he could make a local vegetable oil-grinding machine, but was not given the chance to exercise his idea.

During the discussion, participants said that some parents use children with disabilities as a means of generating income due to the poverty they live in. Likewise, there are some persons with disabilities who beg because they don't have any other choice.

"A woman with albinism was living alone. Since there are beliefs associating albinism with good fortune 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 continues to while being infected with HIV and having skin cancer."

Participant from NGO,
62 years, Dar es Salaam

5. Attitudes towards witchcraft and albinism

The discussion with the peer researchers highlighted that the organs of persons with albinism are used in witchcraft activities. It was reported that there have been meetings with different stakeholders to identify the market for these organs. Although the study could not establish evidence during the above mentioned meetings, participants reported that the organs were most likely sold in Tanzanian goldmines and outside the country. This information was not based on participants' experiences but was based on rumours in the community. It is also perceived that the organs of persons with albinism can bring about success, which is not the case. In addition, some of the traditional healers mislead the community by claiming that organs of persons with albinism are linked to omens of good fortune.

"Organs of people with albinism are perceived to have good luck (nuru ya mafanikio)."

Person with albinism,
32 years, Kibaha District

"There was an incident whereby some girls in the community wanted to have a relationship with a person with albinism so that they can have good fortune. Most of the time, traditional healers mislead society for things that are not realistic."

Participant from NGO group,
50 years, Dar es Salaam

There is still unfounded belief among traditional healers and community members linking albinism with good fortune. However, the idea of using the organs of persons with albinism as a source of good fortune were refuted within the group discussion and feedback sessions.

"There is no relationship between albinism and good fortune, this is only witchcraft. But there is a belief that one is blessed if one happens to have a child with albinism.""

Participant from NGO,
50 years, Dar es Salaam

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The government issued a circular to protect persons with albinism against attack and abuse, but it has not been fully implemented, as the killings went on despite the existence of the circular. The main reported challenge by the peer researchers was poor law enforcement. One peer researcher recalled an event which happened just before the general election in Mkuranga district where a group of unnamed people wanted to remove the genitals of a person with albinism. They managed only to cut a piece of the person's ear, yet the culprits were not captured.

During the discussion with participants from the NGO group, it was mentioned that politics is perceived as one reason for the killing of persons with albinism because it mostly happens during election periods. Peer researchers explained that people believe politicians are asked by the traditional healers to bring organs of persons with albinism. The following typical statement was recorded:

"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 that had not been the case, we could have experienced a greater number of deaths of people with albinism."

Participant from NGO,
62 years, Dar es Salaam

There was also another case related to a child with albinism who wanted to study, but was met with a lot of challenges. The child was discriminated against by his school friends. He was nicknamed "dili" (meaning "deal") whenever he attended school. He was feeling very sorry as he didn't like the name. He was encouraged by his aunt and grandmother who kept telling him that he should not stop going to school.

It was further reported during the discussion with peer researchers that in the old days, there was a misconception that persons with albinism never die, but they instead get lost. Peer researchers reported that – according to the tradition of the Sukuma tribe in the lake zone – whenever a person with albinism dies, his grave is dug inside the house. There is a similar situation happening currently in the lake region where older women with red eyes are being killed because of suspicions that they are witches. In this case, there is a need to enforce the use of an ordinance witchcraft act (in dealing with witchcraft, several doctrines of ordinary law provided sanctions intended to restore and penalties subject to cruelty of the witchcraft abuses; Mesaki S., 2009) which was established during the colonial period so that older people and persons with disabilities can live like others.

Killings of persons with albinism have created fear among this particular group. This persecution has even disrupted their lifestyles as some of them are now staying at home without work. Children have abandoned school and this has increased their dependence. The following typical statement was reported:

"In Tanga, we started to hear that there were people who were looking for us (people with albinism). My colleagues were making jokes, saying: 'Who is escorting you? Who are you with today?', then I would answer 'I am alone'. Then they would say: 'You know that there are people who want to kill you and you are still walking alone?' When these killings were prolonged, my father had to stop me from leaving the house. He said: 'You should stop doing this business far away from home. You had better stay at home because anything can happen when you are away from the house and it may result in a serious problem.' It is better for somebody to kill you than to cut off your body organs, because you will become even poorer. At this stage we are already poor; when you lose your organs you end up in extreme poverty."

Person with albinism,
36 years, Kibaha District

6. Relationship difficulties and marriage breakdowns

During the discussion about this topic, peer researchers reported that some parents take over the roles of choosing a fiancée/life partner for their children. They added that this might be among the reasons for difficulties and marriage breakdowns. One of the participants said:

"Parents have much influence about their children's marriage. They can sometimes dictate that their daughter or son will marry so-and-so. However, these young men could also have their own choice which contradicts their parents' selections."

Participant from NGO,
48 years, Dar es Salaam

In addition to the above, peer researchers reported that some parents might be after the wealth of their child's spouse. This was among the reasons for conflicts within families, as well as marriage breakdowns.

A lack of empathy for persons with disabilities was also reported as a contributing factor for family difficulties. Peer researchers reported that family difficulties also happen as a result of the looting of properties belonging to persons with disabilities.

Most women are dependent on their husbands' incomes. Sometimes a marriage is seen as a favour to women with disabilities. The following quotes put it clearly:

"Most families live by depending on the husbands' income. Usually when a man terminates his employment contract, his family gets into trouble. Most men who marry people with disabilities usually discriminate against their wives, whereas women do not discriminate against men with disabilities."

Participant from NGO,
48 years, Dar es Salaam

"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 child for a period of three months. However, my husband refused to provide me with support. He supports only his child. It is OK if he has decided to not support me. I cannot force him to support me if he has decided not to."

Person who is a hearing impairment,
35 years, Kibaha District

Likewise, there was another case whereby an older person was neglected by his family and community members just because he was poor and had no income. During the discussion, participants reported that older people are not involved in social development issues in their respective localities. Their expertise is not utilised in village government-related activities either, regardless of the post they had been serving in the past.

Families of women with disabilities have also reported being sometimes abandoned at their homes with little support. Moreover, unfair distribution of wealth to persons with disabilities has also featured in the stories. Older people and persons with disabilities have reported that they receive little or no share of inheritances.

It is evident from this study that poverty may be a contributing factor for someone losing his or her rights. For example, one woman could not inherit money from her deceased child who had been working as an immigration officer. The woman had been heavily dependent on her late child for everything and was now left with a grandchild. The woman is now living a difficult life as she has no other income. During the discussion, peer researchers felt that the Ministry of Health and Social Welfare department does not receive enough funding to follow up issues related to older people and persons with disabilities. However, this was challenged by an NGO peer researcher working in the department.

There was another case related to a person with disability who wanted to get married and faced some challenges just because he had a disability. In this story, he approached his fiancée and proposed to marry her and she agreed, but the people surrounding the woman were unhappy and discouraged her from getting married to someone with a disability:

"Later on, after completion of my studies, I wanted to marry but I faced some challenges to the first lady I approached. Although she agreed to marry me, she was discouraged from getting married to a person with disability. I went to the second one, whereby the experience was similar to the previous. I told my mother that I do not expect to marry and she asked me why. I told her that there was no woman who loved me, but later on – I remember it was at the end of 2004 – I was lucky to meet this woman with whom I live to date. I told her my intention, thank God she understood me, but she experienced a similar situation with the people surrounding her. Some of her friends told her: 'You got married to a person with disabilities, ahh!' Many were sorry, but she ignored them."

Person who is blind,
41 years, Nachingwea District

Peer researchers proposed the inclusion of advisors, such as law professionals, on various aspects of social welfare in order to help older people and persons with disabilities.

7. Sexual violence and gender issues

With regards to sexual violence, peer researchers reported women with disabilities being exploited sexually, threatened and mistreated. Furthermore, peer researchers reported that men who marry women with disabilities tend to be convinced by their friends to leave their partners. In addition, some of the women had concerns of being harassed sexually, including being made to perform anal sex against their will. The detail of the story is as follows:

"My husband decided to divorce me because he forced me to have anal sex and I refused. That was my first reason for our separation – I thought I could not do it. I told him that I could not do it because it is forbidden in our religion and it is not safe for human health. The man became angry and proposed our separation. He stopped providing the services. He confused me and left me with nothing. I asked for my divorce and he gave it to me. I stayed alone."

Person with a hearing impairment,
35 years, Kibaha District

There have also been concerns around people with intellectual disabilities. Stories have shown a notable amount of sexual harassment, as is described in the following quote:

"We met a girl with intellectual disability living comfortably with her parents in Kimanzichana village. But what we found when we visited her was really shocking. Her parents had found a man whose role was to take care of her sexual desire. We felt very sorry when we got the information because the girl could have chosen her own fiancé. But the parents informed her that they would choose someone. We tried to discuss this issue with the parents, but could not reach a consensus. The parents said that they had the right to select someone who could take care of their daughter. We felt very sorry because the girl had the right to select someone to marry herself, but we think this was done because she was a person with disabilities."

Participant from NGO,
48 years, Dar es Salaam

8. Poor treatment from family

A lack of support from families was reported as a challenge by persons with disabilities and older people in the study districts. Other reported challenges were the needs of older people and persons with disabilities being ignored. Some children were being mistreated just because of their disabilities. Some parents see a child with disability as a burden and therefore decide to abandon that child with other family members. The following quotes summarise the issues:

"I have encountered a lot of challenges in my lifetime. Firstly, I have little education. I left school when I was at standard six. I was very clever at school. When I reached grade six, my relatives sent me to a village. Village life was difficult and I decided to go back to my father. My father did not give me good support. I stayed at home because they said that a person with ear impairment (deaf) 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."

Person with a hearing impairment,
32 years, Kibaha district

"This child's mother came here and left her daughter with me when she was very young. Her father is alive and lives in Dar es Salaam. The child calls me mother, not grandmother. She has done since her childhood, calling me mama, mama... Her mother came to take the daughter to the traditional healer and later left her with me after the mother and the traditional healer failed to "cure" the child's disability."

Older person,
80 years, Kibaha district

There were some stories of older men and women who reported that they were mistreated by their children. Some of the children who were responsible for taking care of their parents were described as having never shown love and humour towards their parents.

Participants' experience of ageing and disability as shown by coded analysis

As the peer researcher analysis included their opinions on what they considered to be main issues, the analysis was then triangulated by researchers who coded a selection of interviews from the original 106, asking the research question: How did participants experience ageing and disability? without any emphasis on importance of issues. The findings from this coded analysis were validated by the peer researchers through workshops conducted in their own localities.

The first stage of coding simply listed what was happening throughout each story. The second stage linked what was happening in all the stories to find patterns between them. The third stage looked carefully at the patterns and created the common themes emerging from the group of stories. The themes were then grouped into three categories: individual, interpersonal (interaction with friends, family and community) and societal level. This grouping emerged naturally out of the themes.

On an individual level, some participants spoke of having multiple illnesses, at times with one illness triggering another. Many experienced emotional difficulties, such as negative self-perception, stress, various effects on their mental health and, at times, a sense of hopelessness. Many participants had a high exposure to death. Older people and persons with disabilities shared memories of being young, with both positive and negative stories to tell. Older people shared how they felt about young people they came into contact with now, often negatively, though there were also positive instances of help being given by a young family member.

On an interpersonal level, there were various experiences of from both groups. There were stories of domestic abuse and a few about sexual fear. Positive experiences of relationships in the community were common, ranging from being respected for their skills to receiving assistance from the local mosque, Catholic priests and neighbours, as well as support from police, their workplace, peers and family. There were stories of good relationships with neighbours. Negative experiences ranged from health stigmas and mistrust of the capacity of persons with disabilities to exclusion from social activities, taunting when younger for a parent's disability, exclusion from religious activities, a lack of help from young people in the villages, old age being viewed as a sickness, lack of access to toilets and privacy, and resentment from those being relied upon to provide support.

Various stories revealed that traditional methods were encouraged in local communities – with both positive and negative effects. One theme that was specific to disability was fear of extreme persecution and attacks on persons with albinism. Stories about this revealed killing attempts, fear and rejection by others of albinism, and general discrimination that left a psychological impact on those targeted.

A main theme that emerged was the huge impact on primary and key relationships as a result of individual and community experiences, for both persons with disabilities, and to an extent for older people, There were many examples of challenging family relationships and marriage breakdowns. A few stories revealed a strong and positive marital experience, despite poor community experiences.

On a societal level, NGOs related to disability and older people shared a pressing need for more support of their work at a governmental level, both financially and by acknowledging the impact and issues faced. Persons with disabilities experienced political barriers, discrimination in education, being denied work opportunities and poor access to work as a result of a lack of appropriate transport. Both persons with disabilities and older people had difficulty accessing appropriate health care. Some older people shared positive experiences of health care, and persons with disabilities had some positive experiences of school. Both groups shared stories of support from social services and NGOs.

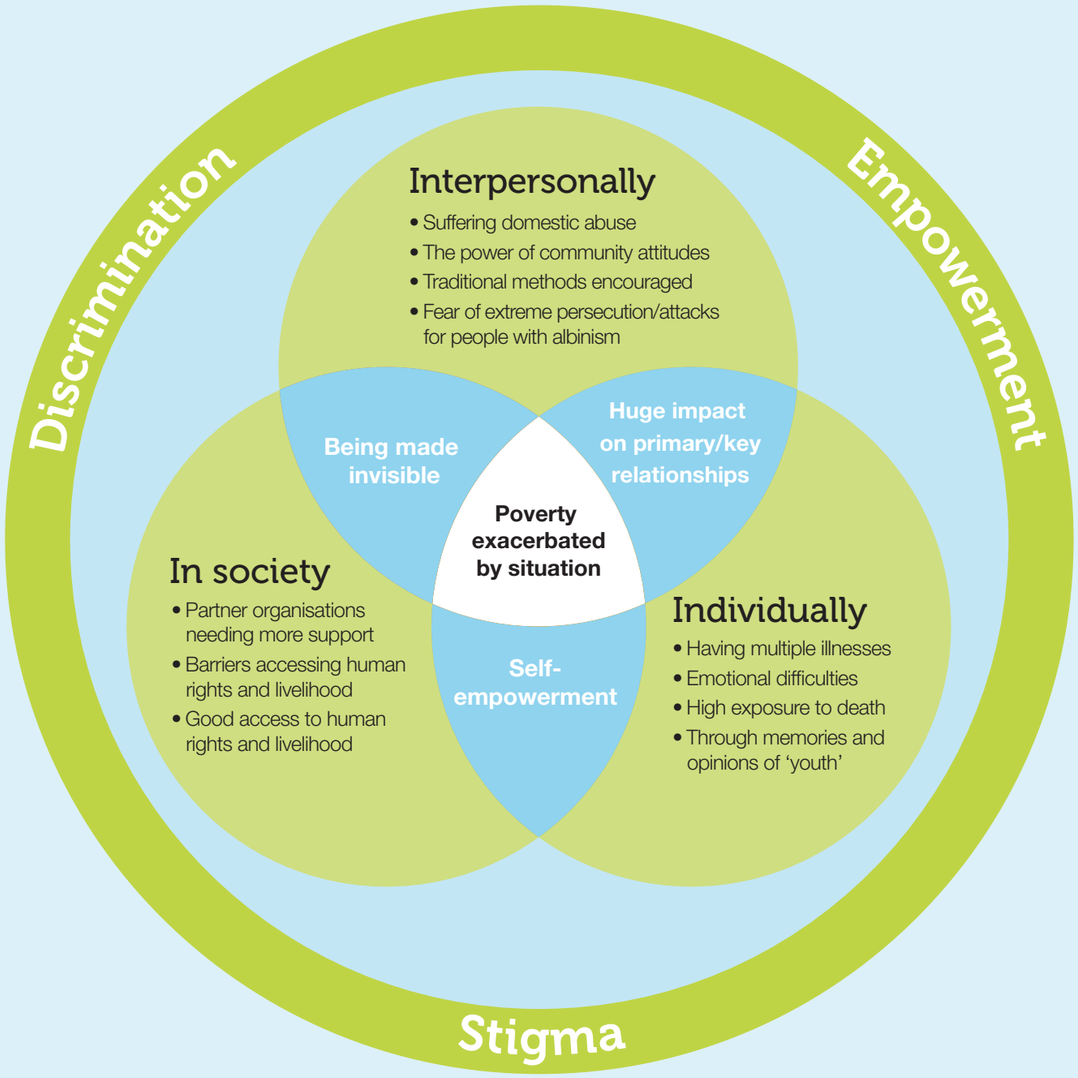
A key theme that emerged from experiences at both an interpersonal and societal level was that a number of persons with disabilities and older people felt as though they were invisible. This, in turn, affected the individual experiences already stated above. A theme that emerged mainly from experiences at both an individual and societal level was the building of self-empowerment and help-seeking behaviour. Some were proud that they were still able to live independently, get married and have children whilst coping with a disability. Others showed a strong sense of self-worth, and one person identified as "a one-person army". Bad experiences led a few to forge an independent life and find their own value.

Often, participants' individual, interpersonal and societal experiences of disability and old age increased their levels of poverty. This created a vicious cycle of poverty which worsened their situation, making them even poorer.

Throughout the stories, there were examples of experiencing stigma and discrimination for both older people and persons with disabilities, but also empowerment – often in the same story. The findings of the analysis are summarised in the following diagram.

Voices of the marginalised – Tanzania

Research question:
How do participants experience ageing and/or disability?



The coded findings were also considered through the lens of the physical, social and attitudinal domains:

The physical domain: both persons with disabilities and older people experienced multiple illnesses, sometimes causing or exacerbating each other. They also described details of their impairments or the effects on their bodies due to older age. Transport issues were raised and injuries from domestic abuse described. Both demographics of participants also described the physical effect of the lack of available medication or ability to afford it.

The social domain: participants described a high exposure to death due to age or illness. Exclusion from social and religious activities was common due to physical impairment but also due to others' attitudes. Some participants in each demographic cited a lack of young people to help practically, though these were mainly older people. Many also had one-off positive stories of community support. Various barriers to accessing human rights were raised, particularly in relation to health systems, but also relating to access to toilets and privacy once there for those with disabilities. Stories of good access to health systems often showed NGOs as instrumental. Access to school might have been available to participants with disabilities but learning was limited due to lack of resources and training and so participation often ceased. This had a knock-on effect on work opportunities, with work places also creating their own limitations.

The attitudinal domain: complexities surrounding domestic abuse emerged, as did extreme persecution of people with albinism. Specific to albinism, two killing attempts were cited, along with others' fear and rejection of albinism, and general discrimination. More generally, people with disabilities often experienced mistrust in their capacity and resentment from those helping them when help was required. One participant with disabilities was hindered from progressing in politics due to others' attitudes, and a number of participants from both demographics spoke about being overlooked; it felt as if they were being made invisible. Older people expressed experiencing neglect. There were several examples of self-empowerment and help-seeking behaviour, showing a strong sense of value. Bad experiences led a few people with disabilities to forge an independent life and find their own value. Families and spouses' attitudes led to breakdowns in relationships for people with disabilities, but there were a few stories revealing a strong and positive marital experience, often in spite of community opposition.

The findings found through the three-tier coding reflect the eight priority areas raised by peer researchers. However, the coding analysis also highlighted that, although emotional distress was apparent throughout the interviews, interviewees and peer researchers did not place emphasis on this as viable evidence in the fight for change for older people and people with disabilities in the Tanzanian context.

Discussion

The study has revealed a number of issues affecting the lives of older people and persons with disabilities, such as a lack of access to education and quality learning, access to health services, issues fed back from NGOs, poverty relating to income and dependence, attitudes towards witchcraft and albinism, relationship difficulties and marriage breakdowns, sexual violence and gender issues as well as poor treatment from family. These issues are interlinked: for example, families of children with disabilities have not paid serious attention to the education of their disabled children. Teachers are not adequately trained to teach children with disabilities, and there are inadequate school infrastructures to support children with disabilities. Contrary to the free education policy for children with disabilities (United Republic of Tanzania, 2014) they have to pay for school fees like other students without disabilities. Recently, the government abolished fees for all government primary and secondary schools, but this should go along with improvement of quality of education provided.

This study has confirmed previous findings (see for example Zitha, 2012) on the benefit of extended families (whereby a family group consists of parents, children and other relatives lives together or in close contact, Dictionary of Unfamiliar Words, 2008) towards caring for older people and persons with disabilities. The study has shown that the extended family system was more beneficial in caring for persons with disabilities and older people compared to the modern family system. Interventions for improving family support to older people and persons with disabilities should consider sustaining these initiatives.

The government through the Prime Minister's Office – Regional Administrative and Local Government (PMO – RALG) has mandated that older people and persons with disabilities be exempt from fees at any government facility (United Republic of Tanzania, 2007). The reality, however, is that older people and persons with disabilities are asked to pay for services such as consultation fees and medicines. The implementation of the circular about free medical services will require the introduction of legislation on older people as a way to enforce the policy. Advocacy at community and health-system level is also needed to ensure the implementation of the circular so that older people and persons with disabilities can benefit from free health services.

The issue related to the implementation of the bill on free medical services is not limited to the health sector but affects other sectors as well. Older people and persons with disabilities have a number of challenges relating to income and dependence which have been reported elsewhere (Hubbard G. et al., 2003; Yeo R. and Moore K., 2003). Lack of employment was also mentioned as a challenge for persons with disabilities (Yeo R. and Moore K., 2003; Wan N., 2003). Although the national employment policy mandates the government and associations of persons with disabilities work in collaboration with other stakeholders to undertake affirmative action to enhance the employability of persons with disabilities (United Republic of Tanzania, 2008; United Republic of Tanzania, 2004), its implementation is far from complete. This study found that older people are not involved in different social development issues in their respective localities. Their expertise is not tapped in village government-related activities regardless of the post they had been serving while in government.

People with albinism are exposed to stigma all over the world, including the United States (Wan, 2003) and Africa (Brocco G., 2015). In Tanzania, like other countries, killings of persons with albinism have created fear among this particular group in society (Brocco G., 2015). Labelling of people with albinism using undesired names such as "dili" has also been reported elsewhere (Brocco G., 2015). In brief, all these issues have disrupted the lifestyles of people with albinism as some of them are now staying at home rather than going out to work. Furthermore, children with albinism have abandoned school, increasing dependence among this particular group. At national level, peer researchers identified that the government must reinforce the law to stop the persecution and killing of people with albinism. However, limited knowledge exists on what is referred to by communities as "albinism and good fortune". This lack of knowledge complicates the process of inclusion/acceptance of persons with albinism in their communities (Wan N., 2003; Brocco G., 2015). In Tanzania, people with albinism have hardly had a platform to tell their stories. This study has attempted to bridge this gap. More research is needed so that concrete facts can be established on the source of killings of people with albinism.

With regards to family difficulties and marriage breakdowns, as in many other countries where parents have an autonomous role over their children (Dixon S.V. et al., 2008; Emery R.E., 1999), peer researchers discussed how the major source of marriage difficulties and breakdowns were mainly caused by the parents taking on the role of choosing their children's spouse. It was also noted how, in Africa, some parents give their daughters to men for the purpose of accumulating wealth (Aboderin I., 2004; Mace R., 1998). This was a concern discussed by peer researchers in the study areas. It was quoted to be a source of confrontation between the parents and an important contribution to marriage breakdown.

Peer researchers identified a number of policy recommendations which would need to be taken on board by community leaders and policymakers in order to respect, protect and fulfil the rights of older people and persons with disabilities in Tanzania. Locally, peer researchers realised that they had an active role to play in raising awareness of older people and persons with disabilities. For instance, they decided that they need to speak up during village meetings and actively engage with the government to implement the National Disability Policy of 2004 (United Republic of Tanzania, 2004). They decided to take a lead in providing sexual education to communities, as well as educating and empowering families of older people and persons with disabilities so that they can receive better support and provision of services.

Conclusion and recommendations

This study serves as a reminder that the situation for older people and persons with disabilities is complex, and to serve it best requires listening carefully to the voices and stories of both groups and the NGOs that support them. They may be the voices of the marginalised, but when listened to properly, have the potential to be the voices of the empowered.

Participants' experience of ageing and disability

Participants' physical, social and attitudinal experiences often exacerbated their levels of poverty, which then worsened their experiences, in turn further deepening their poverty. The study has informed policy recommendations that push to break this cycle. It is important to improve physical, social and attitudinal experiences, but also to highlight the right to individual needs and the importance of the emotional implications of meeting them. Policymakers should legislate the national policy on ageing so that there is a binding legal framework under the new Ministry of Health, Social Development, Gender, Older People and Children.

Access to education and quality learning

With regards to the above-mentioned bottlenecks on education, participants in the group discussions said that children with disabilities should be cared for like other children and should not be ignored. Children with disabilities should be treated equally with other children. The government should train teachers and provide a supportive environment and special equipment to children with disabilities so that they can study like their peers. There is also a need to create awareness for parents of children with disabilities, and the community as a whole, because children with disabilities have equal rights to access education. It was also recommended by the peer researchers that there should be a revision of the primary school curriculum to teach children about respecting and caring for older people and persons with disabilities in order to have an impact on future generations.

Access to health services

Peer researchers recommended that older people and persons with disabilities should conduct regular check-ups in order to detect and prevent diseases such as cancer, which require early diagnosis. They also agreed to return to their communities and raise awareness of this issue. Likewise, social welfare officers should make frequent visits to villages to assess the health status of older people and persons with disabilities in order to design feasible and appropriate health care and management interventions. Persons with disabilities should be given their own window/desk while in hospital. The infrastructure should be made accessible to persons with disabilities, for example the building of health facilities should include the construction of ramps and toilet facilities for persons with disabilities. Hospital staff should ensure that the complaints of older people and persons with disabilities are respected. The majority of the peer researchers suggested that health care providers should be trained in sign language in order to facilitate communication with their patients. It was also recommended that National Health Insurance be compulsory in order to take care of older people and persons with disabilities. Insurance schemes should cover all essential drugs. Advocacy is also needed to ensure that the government implements the circular for free health care to older people and those with disabilities.

Issues fed back from NGOs

Peer researchers suggested that there is a need to improve the care services offered by government and NGOs to older people and persons with disabilities. NGOs should also work as a pressure group to facilitate these services. For example: NGOs should employ additional professionals who can advise older people and persons with disabilities on various issues related to their wellbeing, as currently this is not the case. This is necessitated by the fact that most of the services provided by NGOs are on a voluntary, unpaid basis. Instead, NGOs should have their own projects or other means to sustain themselves. It was therefore proposed that NGOs initiate projects and work together to help care for older people and persons with disabilities. Another proposal by the NGOs group was to be transparent about their work to targeted groups and the community at large. Likewise, NGO study participants proposed putting pressure on the government to allocate enough budgets for the care of older people and persons with disabilities.

It was recommended that the SHIVYAWATA – Tanzania Federation for Disabled People (TFDP) organisation should join forces and make sure that they continue a dialogue with the government to ensure the availability of funding. Likewise, the implementation of the National Disability Policy of 2004 should be taken into consideration. It was also suggested that NGOs should not only provide financial assistance as seed money/capital support to persons with disabilities, but also give advice which could help to shape their lives. During the discussion, participants of NGOs reminded themselves about working as a network in helping persons with disabilities.

Poverty relating to income and dependence

Regarding what should be done to tackle the challenges related to income, peer researchers suggested that rather than waiting for support, older people and persons with disabilities should be creative and establish income-generating activities which could improve their livelihoods. Moreover, the provision of entrepreneurship skills to older people and persons with disabilities could help to reinforce this. The expertise and experiences of older people and persons with disabilities should be tapped into development activities within their communities. It was also proposed that people should get prepared by saving money where possible, in order to minimise dependency in their old age. Likewise, peer researchers requested that the output of the study be used to educate older people and persons with disabilities about their experiences within a socio-cultural context.

Attitudes towards witchcraft and albinism

In their group discussion, peer researchers recommended conducting community awareness about the medical conditions associated to albinism, as well as 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 also be prosecuted.

Relationship difficulties and marriage breakdowns

During the discussion, the majority of participants proposed the establishment of income-generating activities to empower women with disabilities. Another proposed solution was to provide entrepreneurship skills to the families of persons with disabilities in order to strengthen household economies. This includes households of older people and persons with disabilities with low socio-economic status. Likewise, another suggestion was the creation of community awareness strategies to sensitise people on issues related to persons with disabilities, including their experiences, challenges and needs. In addition to the above, community health workers who normally visit households to assist families should be empowered to continue visiting the households. There was also a need to counsel men so that they can take their responsibilities of caring for their families and children with disabilities seriously. Likewise, it was also recommended that parents should not interfere with the marriages of their children with disabilities, for example choosing their spouses. Lastly, village chairpersons should have a list of older people and persons with disabilities in their respective localities in order to facilitate smooth coordination and support for these marginalised groups. However, other participants in the NGOs group reported that it is the responsibility of the NGOs to have a list of older people and persons with disabilities.

Sexual violence and gender issues

Peer researchers recommended taking a lead in providing sexual education to their respective communities for better research impact. Measures should be taken to raise awareness on gender equality and discrimination in the communities, including the need to report physical, verbal and sexual abuse to the police. This should provide lessons to those with bad intentions or who mistreat persons with disabilities. This study has also shown that some people take advantage of persons with disabilities to benefit themselves. By having legislative measures in place, these behaviours will be reduced.

Poor treatment from family

Families taking care of older people and persons with disabilities should be sensitised to the needs of these marginalised groups. The government should provide counselling to parents of children with disabilities on how to provide better support and guidance. In addition, the Ministry of Health and Social Welfare office should create awareness among village leaders in how to educate communities on living with marginalised 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. In addition to the above, the older people should ensure that their organisations protect their interests.

Weaknesses of the study

One of the limitations of the study was that both groups – older people and persons with disabilities – were literate and this would likely to have biased the group perspective away from the greatest poverty. This study was categorised as low-risk; however we were not necessarily made aware whether any of the participants had themselves experienced sexual abuse. Issues surrounding sexual abuse were extremely sensitive and it is very likely that some stories were not shared, especially those that might have caused psychological distress. Similarly, some of the participants with albinism may have held back on sharing their stories in order to avoid emotional distress. Finally, study planning had not placed emphasis on aftercare, such as linking participants with local practitioners for support following the study.

For future learning, it would have been better to incorporate the three-tier coding into the analysis workshops, so that peer researchers were part of that stage rather than validating its findings. There was also some uncertainty with roles and relationships which improved as the group fully understood the methodology.

Another weakness to recognise is not always being explicit about factors affecting older people more or less than persons with disabilities. The study did not explore in depth the intersections between older people and persons with disabilities, which a future study could address. We would also like to acknowledge the limitation of the small sample in providing a valid basis for concrete policy recommendations. Finally, it would have improved the study to explicitly ask participants if they experienced any psycho-social or intellectual disabilities. The transcripts implied that these might well be present but there is no evidence collected relating to this.

Strength of the study

This study has informed efforts to provide services for and improve the lives of older people and persons with disabilities in Tanzania. The body of evidence reported here contributes to knowledge gaps which can be drawn upon by stakeholders in Tanzania and beyond. In terms of study design, the research has contributed to bringing together CBPR and disability. Rich data has been collected and there has been clear ownership of findings by the peer researchers. The approaches used will help to build strong and inclusive policies which will contribute to inform implementation of the 2030 Agenda. The study has also contributed to building ways of engaging with CBPR in the context of social inclusion and disability, through its strengths and weaknesses. Accommodation and transport relating to participants' needs were well considered.

The peer researchers identified and proposed policy recommendations which should be taken on board by community leaders and policymakers in order to respect, protect and fulfil the rights older people and persons with disabilities in Tanzania.

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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 People (UNCROP).
- Promote the full and equal participation of older people and persons with disabilities in policy making at all levels, with systematic processes for meaningful engagement.
- Increase funding and improve data collection and analysis mechanisms on both disability and ageing to increase knowledge.
- Raise awareness about the experiences of older people and persons with disabilities to reduce stigma and discrimination.
- Ensure SDGs-compliant development to provide public services that are inclusive to older people and persons with disabilities.

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Annexes

Annexe 1: Interview guides for NGO peer researchers

Story prompts for NGO peer researchers:

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

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

Follow-up questions

Clarifying questions – to make things clear

eg Who? What? Where? When?

Probing questions – to get more information

eg What happened next? Who else was involved? Is this typical or unusual?

Analysis questions – to understand why.

eg Why did you tell me this story?
Why do you think this happened?
What lessons does this story give you?

Documentation

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

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

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

Annexe 2: Interview guides for peer researchers (older people and persons with disabilities)

Story prompts for peer researchers:

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

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

Follow-up questions

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

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

Analysing the stories

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

Documentation

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

Annexe 3: Information sheet

Information Sheet

Participatory research with persons with disabilities and older people in Tanzania

[Greeting] My name is ..... You are being invited to take part in this research project. Before you decide, I will explain the project to you and what we will ask you to do. You are also free to ask questions. This research is being done by the Ministry of Health and Social welfare (MoHSW), Ifakara Health Institute (IHI), Sightsavers, HelpAge International and ADD International.

What is the project about?

Globally, persons with disabilities and older people face widespread exclusion. They are routinely left out from participating in social, economic and political activities and processes, including national and international development policy, practice and research. Exclusion reinforces the disproportionately high number of people living with disabilities and older people among the poorest of the poor.

We are currently carrying out a study so as to provide evidence on the specific nature and experiences of older people and persons with disabilities from their own perspectives in rural and urban setting of Kibaha and Nachingwea. To do this we will be talking to a wide range of people living with disabilities and older people.

Why have I been selected to take part?

The project is taking place in your district, and we are interviewing people with disabilities, older people and people working with Non-Governmental Organisations (NGOs), as we also want to understand the experiences of NGOs working with older people and people with disabilities in your area. You have been selected to participate in this research as you are one of the above I mentioned above.

What will happen in I agree to take part?

If you agree to take part, we will ask you to tell us your experiences as NGO dealing with people with disabilities or older persons. The purpose is to discuss a range of topics of this marginalised group. During our interview, we will take your picture if you allow us to. The picture will only be used for the purpose of the report of the research findings.

All the information you give us will be kept completely private, so no-one will know what you say with the exception of the people in this research. Your name will not appear in any documents or reports. The discussions will take place in a quiet, private location.

We might like to record the discussion/ interview, to remind us later of exactly what was said. As we will record the interview, the tapes will be kept in a secure place, and after the information has been extracted the recordings will be destroyed. But if you are not agreeable to this we will just make written notes. We might want to quote what you say, but without linking your name to the quote.

Are there any direct benefits to me?

No, there are no direct benefits to you taking part in this study. However, the outcomes of this survey will be used by MoHSW, IHI, Sightsavers, HelpAge International and ADD International in Tanzania and internationally as part of their advocacy to highlight the reality of the lives of older people and persons living with disabilities. The findings will be written up in a report, and also for publication in national and international medical journals, however, your name will not appear to any of these documents.

Your participation to this research is voluntary. You are free to participate or not to without punishment or any complaint. Though, we will be happy if you agree to participate in this survey. If you decide not to take part in this study, this will not affect the service you receive from the health care facilities or anywhere else.

Are there any risks to taking part?

No, there are not any risks in participating in this survey. However, this will take some of your time to tell your experiences. No, payment is not required to participate in this study. You may choose not to answer some of the questions we will ask you if you don't wish to do so.

Will I be compensated for my time?

No, we envisage that the discussion will take a maximum of one hour. No payment or compensation is provided for study participants. Your participation is free of charge.

If you have any question we will be happy to answer it.

For further information about this study please contact Bakar Fakih working with Ifakara Health Institute. If you would require information from the ethical committee you may contact the secretary (Beverly Msambichaka) of the Ifakara Health Institute Review Board: **0659165230**.

Annexe 4: Consent form

Consent form

Participatory research with persons with disabilities and older people in Tanzania

[Greeting] My name is .....
You are being invited to take part in this research project. Before you decide, I will explain the project to you and what we will ask you to do. You are also free to ask questions. This research is being done by the Ministry of Health and Social welfare (MoHSW), Ifakara Health Institute (IHI), Sightsavers, HelpAge International and ADD International.

What is the project about?

Globally, people with disabilities and older people 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 disabilities and older people among the poorest of the poor.

We are currently carrying out a study so as to provide evidence on the specific nature and experiences of older people and persons with disabilities from their own perspectives in rural and urban setting of Kibaha and Nachingwea. To do this we will be talking to a wide range of people living with disabilities and elderly people.

Why have I been selected to take part?

The project is taking place in your district, and we are interviewing people with disabilities, older people and people working with NGOs, as we also want to understand the experiences of NGOs working with older people and persons with disabilities in your area. You have been selected to participate in this research as you are one of the above I mentioned.

What will happen in I agree to take part?

If you agree to take part, we will ask you to tell a story about your experiences as NGO working with older people and people with disabilities. The purpose is to discuss a range of topics about this marginalised group. We may also take your picture during interview, if you allow us to. The picture will only be used for the purpose of the report of the research findings.

All the information you give us will be kept completely private, so no-one will know what you say with the exception of the people in this research. Your name will not appear in any documents or reports. The discussions will take place in a quiet, private location.

We might like to record the discussion/ interview, to remind us later of exactly what was said. As we will record the interview, the tapes will be kept in a secure place, and after the information has been extracted the recordings will be destroyed. But if you are not agreeable to this we will just make written notes. We might want to quote what you say, but without linking your name to the quote.

Are there any direct benefits to me?

No, there are no direct benefits to you taking part in this study. However, the outcomes of this survey will be used by MoHSW, IHI, Sightsavers, HelpAge International and ADD International in Tanzania and internationally as part of their advocacy to highlight the reality of the lives of older people and persons living with disabilities. The findings will be written up in a report, and also for publication in medical journals, however, your name will not appear to any of these documents.

Your participation to this research is voluntary. You are free to participate or not to without punishment or any complaint. Though, we will be happy if you agree to participate in this survey. If you decide not to take part in this study, this will not affect the service you receive from the health care facilities.

Are there any risks to taking part?

No, there are not any risks in participating in this survey. However, this will take some of your time to tell your stories to us. No, payment is not required to participate in this study. You may choose not to answer some of the questions we will ask you if you don't wish to do so.

Will I be compensated for my time?

No, we envisage that the discussion will take a maximum of one hour. No payment or compensation is provided for study participants. Your participation is free of charge.

If you have any question we will be happy to answer it.

For further information about this study please contact the secretary (Beverly Msambichaka) of the Ifakara Health Institute Review Board: **0659165230**.

Do you agree to participate? **Yes** ☐ **No** ☐

I have understood the content of this survey, and what is needed from me, and the consequences of my participation.

My questions regarding this survey have been answered by

_____

(Peer Researcher's Name).

I understand that I can withdraw from participating in this survey any time without giving a reason, without affecting my eligibility for medication and to the authority of this survey. I agree to participate.

Person with Disabilities/Older person

Name _____

Age _____

Location _____

Job _____

Type of disability _____

Mobile number _____

Signature (Thumb print) _____

Witness

Name _____

Signature (Thumb print) _____

Date _____

Annexe 5: Report validation workshop

What is a validation workshop?

This was an activity planned to verify if the compiled information is what was said during the analysis workshop held on 28th September to 8th October, 2015 at Bagamoyo. The report was validated when it was complete in its first draft.

When and where did the validation workshop took place?

The validation workshop meetings took place on 24th November 2015 in Kibaha, 25th November 2015 in Dar es Salaam and 4th December 2015 in Nachingwea. With the exception of the NGO validation workshop which was held in the IHI office conference room, the rest of the two workshops were held in venues which were accessible and friendly to the peer researchers in the respective districts.

Who participated in the validation workshops?

The validation workshops were attended by the peer researchers from their respective localities i.e. Nachingwea and Kibaha (for community peer researchers) and Dar es Salaam for NGOs peer researchers. The meetings were coordinated by the research team from Ifakara Health Institute. Sightsavers UK and Sightsavers Tanzania who attended two of these meetings which were held in Dar es Salaam and Kibaha. There was a note taker in the meetings to capture what were said and discussed. A sign language interpreter was available in Kibaha and Nachingwea.

What was the aim of report validation workshops?

The aim of this validation workshop was to validate the report the research team have compiled from the peer researchers' analysis. It was meant to ask the peer researchers who participated in the generating of the information "is this what you said during the analysis workshop?".

The report findings were shared with the peer researchers for them to read prior to the validation meeting. The report was either shared through emails for most of the NGOs peer researchers or through hard copies to the community ones.

To validate and comprehend the analysis which was done in the UK, the peer researchers were asked if the findings gathered from the question: "How do participants experience ageing and/or disability?" were in line with what they found.

What happened during the validation meeting?

The research team presented the report to the peer researchers. The presentation was based on the overview of the study, what was generated from the main priority areas and the UK analysis. This was followed by discussion from the peer researchers. During the validation workshop, the peer researchers discussed the report in a group. Peer researchers discussed and helped to provide more quotes and examples from the participants' stories. The sessions were later followed by the feedback. The peer researchers accepted that the UK analysis conformed to what the stories give out in comprehension.

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 policy 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 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.”