



Missing millions:

How older people with disabilities are excluded from humanitarian response

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HelpAge

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HelpAge International is a global network of organisations promoting the right of all older people to lead dignified, healthy and secure lives.

Missing millions:

How older people with disabilities are excluded from humanitarian response

Published by HelpAge International
PO Box 70156, London WC1A 9GB, UK

Tel +44 (0)20 7278 7778

info@helpage.org

www.helpage.org

Registered charity no. 288180

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Research by the International Centre for Evidence in Disability (ICED), London School of Hygiene & Tropical Medicine (LSHTM) and HelpAge International



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Authors: Phillip Sheppard and Sarah Polack, International Centre for Evidence in Disability at London School of Hygiene & Tropical Medicine and Madeleine McGivern, HelpAge International

Edited by Celia Till

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Executive summary

Up to 14 million older people with disabilities may be affected by humanitarian disasters. These people are among those most at risk, yet little is known about their particular experiences. Their rights and needs are widely overlooked in humanitarian response.

At the heart of humanitarian action are four principles: humanity, neutrality, impartiality and operational independence. These principles afford everyone the right to safe and dignified access to humanitarian assistance and protection without discrimination and on an equal basis with others.

Humanitarian policy and programming is increasingly focusing on the inclusion of older people and people with disabilities. However, it is often assumed that older people and people with disabilities can be supported simply by implementing needs-based assistance; there is limited evidence and attention paid to the intersection of older age and disability, the particular experiences of older people with disabilities in humanitarian crises, and the extent to which their rights are upheld in humanitarian contexts.

Research questions

The aim of this study was to explore the experiences of older people with disabilities across a range of humanitarian settings. The questions we asked were:

- **Do older people with disabilities have additional needs and challenges accessing humanitarian assistance and protection?**
- **What factors facilitate or limit access by older people with disabilities to humanitarian assistance and protection?**
- **To what extent is humanitarian response inclusive of older people with disabilities?**

We used several complementary methods to answer these questions. First, we conducted a systematic literature review of published studies that included research findings on older people with disabilities affected by humanitarian crises. We also reviewed key online humanitarian guidelines to explore how far they explicitly address older people with disabilities.

We analysed data from six population-based disability surveys comparing the living situation of older people with and without disabilities. These included databases from two crises-affected populations in Haiti (post-earthquake) and Palestine. Given the scarcity of data available from humanitarian contexts,

we also analysed data from four non-humanitarian settings to explore more broadly the situation for older people with disabilities – India, Guatemala, Cameroon and Nepal.

We interviewed older people with disabilities, members of their families and local key informants in two conflict-affected populations in Ndutu and Mtendeli refugee camps in Western Tanzania, and Donetsk and Luhansk regions of Eastern Ukraine to find out about their experiences. We also interviewed staff of five international agencies working in humanitarian response to explore how their policies and programmes respond to the needs of older people with disabilities.

Key findings

We found that older people with disabilities fared worse than older people without disabilities. We identified a number of barriers that made it harder for them to escape from danger and exercise their right to humanitarian assistance and participation.

Older people with disabilities faced physical barriers such as having to travel long distances to distribution points, lack of accessible transport, and inaccessible houses, toilets and public buildings. It was clear that low-cost adaptations such as wheelchair ramps could make a big difference. Older people with disabilities also faced attitudinal barriers, and at times were made to feel humiliated trying to access their rights in humanitarian settings. Thirdly, they faced institutional barriers, such as a requirement to collect food aid and social protection payments in person. These combined to threaten their right to independence, dignity and participation.

We also identified factors that enabled older people to exercise their rights. Families, neighbours and social structures were particularly important. Transport, proximity to services and home visits by health staff, community workers and “incentive workers” in camps (providing information to older people) also made a significant difference.

Interviews with staff from international organisations highlighted a disconnect between age-focused organisations and disability-focused organisations, from local to global level, and concerns about collecting data on disability and ageing, meaning that older people are at risk of being missed out of efforts towards disability inclusion and vice versa.

Specific issues

Our findings highlight particular issues facing older people with disabilities in humanitarian crises:

More risk escaping from danger

Our findings suggest that older people with disabilities may be at more risk escaping from conflict or natural disasters. Prolonged exposure to disasters also puts a strain on their physical and mental health. Older people with disabilities were more at risk of being left behind while others fled. A woman in Tanzania recalled her experience:

“There were helicopters flying above and shooting down. I stayed in a hole for three days without any food or drinking water.”

Barriers to accessing social protection and work

Older people with disabilities are at more risk of poverty. Our findings show they have higher healthcare needs and expenses, and are less likely to work. In Ukraine, older people with disabilities described difficulties claiming their social pension. A 65-year-old man told us:

“Every three months, they have to take me down from the fourth floor and bring me back up again. I’ve told them that it would be better if a postman could bring my pension to the flat. They say that’s not permitted for resettlers. They make fun of the resettlers and disabled people.”

Older people with disabilities in refugee camps in Tanzania said they wanted to work but were missed out of livelihoods programmes. A 62-year-old man said:

“I need capital, so that I can set up a business such as selling some materials while I sit at home.”

A 90-year-old woman told us:

“I feel sad that I can’t do the things I did before. I used to cultivate some land and be independent, but I can’t do that now. I used to have visitors and manage to give them something, but not any more. I can’t do anything. This upsets me a lot.”

Barriers to accessing health and rehabilitation services

The research shows that older people with disabilities are more likely to experience health problems than older people without disabilities. Older people with disabilities were, therefore, likely to be disproportionately affected by shortages of medicine in Tanzania, and by physical barriers to access and high costs of healthcare and medication in Ukraine.

Barriers to accessing food and other essentials

Although many older people with disabilities said they could access humanitarian assistance, particularly with support from family and friends, many others are at risk of missing out on humanitarian aid distribution due to physical and institutional barriers. Difficulties caused by having to travel long distances to access humanitarian aid, a lack of transport and the requirement to go in person to collect food and other essentials may be exacerbated by ill-health and fatigue, which can be more common in this group.

Further, the fact that older people with disabilities are more likely to be poor puts them at risk of not getting enough to eat. A woman from one of the camps in Tanzania told us:

“Sometimes I cry and tighten a rope around my stomach and sleep on my stomach because I’m so hungry.”

Unsuitable housing and poor living conditions

The research suggests that older people with disabilities may be disproportionately affected by poor housing conditions and lack of household items such as mattresses. Inaccessible buildings meant they were more likely to be housebound, socially isolated and lack privacy. Inaccessible toilets increased their dependency and deprived them of their dignity. A man in Tanzania told us:

“I have no privacy. Living in the same house as my grown-up children isn’t good at all.”

The homes of older people with disabilities may be in poorer condition because they find it harder to keep them in good repair. Sleeping on rough floors exacerbates existing health conditions. A man in Tanzania told us:

“I sleep on the floor. I don’t even have a mattress. My back always hurts when I wake up. I don’t have any energy.”

Insecurity and discrimination

Although many older people with disabilities in Ukraine and Tanzania said they were well treated by their communities, some had experienced discrimination based on age and disability. In Ukraine, some were made to feel humiliated by health and social security staff. In Tanzania, they felt forgotten about because of their age, were told by younger people to leave the camp, and were accused of faking poor health to get money. Some felt vulnerable to theft when collecting their pensions in Ukraine, and some had had household items stolen in Tanzania. A woman in Tanzania told us:

“I can’t tell if it’s safe here or not. The kitchen utensils that I was given were stolen when we were still in the main tent. My children weren’t around and I can’t see.”

Threats to dignity and independence

The research highlighted threats to dignity in the two conflict-affected settings. These included a lack of privacy in crowded houses, inaccessible toilets and humiliating experiences of collecting social pensions in Ukraine. Lack of independence was also a common concern which, in turn, was damaging their wellbeing. A man in Tanzania told us:

“I have no privacy. Living in the same house as my grown-up children isn’t good at all.”

Social isolation and loneliness

Social isolation was a common experience of older people with disabilities in Tanzania and Ukraine. Few of the people we talked to said they took part in social events or meetings outside their house or shelter. Their experience corresponded to data analysis showing that older people with disabilities participate less in social, community and civic life than older people without disabilities. The few people who did take part in social gatherings found it beneficial. A relative of an older woman in Tanzania said:

“When she has the energy, she can use her walking stick to go and worship. She can talk to other people. She can be happy.”

The interviews suggested that older people with disabilities are not being well consulted or included in decision-making processes about humanitarian action or issues affecting their lives. A man in Ukraine said:

“The main problem is that when people lower their voice at a meeting, I can’t hear them. I’m not involved.”

Risks to mental health

Our findings suggest that older people with disabilities may be more vulnerable to poor mental health because they have fewer opportunities for social participation and increased risk of poor health and pain. Prolonged direct exposure to conflict, loss of their previous role in the family, loss of independence and worries about insecurity also contribute to worse mental health. A man who had been shot during fighting in Burundi said:

“I feel very bad, now that I realise I won’t be able to take care of myself. It’s as if I’m dead.”

A man in Ukraine said:

“At night I watch the time go by. I can stay awake until 3.00am. I mistake the sound of thunder for bombing. I’m very nervous.”

Missing from humanitarian response

Many humanitarian policies, guidelines and programmes increasingly aim to be inclusive of age and disability. However, representatives of international organisations suggested that the needs of older people with disabilities were often not well met. One reason is a disconnect between organisations and programmes focused on older people and those focused on people with disabilities. Older people risk being left out of efforts towards disability inclusion and vice versa.

Further, although humanitarian agencies agree that inclusion should be cross-cutting among all organisations, in reality, non-specialist organisations often rely on disability- or age-focused agencies to deliver initiatives targeted at people with disabilities or older people. Despite recognising the importance of including older people with disabilities in planning humanitarian responses, representatives of international organisations suggested this was not being well achieved.

A summary of the needs, risks, barriers and enablers for older people with disabilities identified by the different components of our research is given in the table on pages 8 and 9.

Conclusions

Our research identified a number of factors that promote the right of older people with disabilities to safe and dignified access to humanitarian assistance. These included the provision of rehabilitation and assistive devices, ensuring proximity to services and aid distribution or provision of transport to these services, as well as assistance from family members, and home visits by community, health, and social workers which promoted independence, inclusion and participation.

However, the research also identified physical barriers (such as distance, lack of transport and inaccessible houses and public buildings), attitudinal barriers (such as being told to go away) and institutional barriers (such as requiring people to be physically present to claim social protection and humanitarian assistance) that are likely to disproportionately affect older people with disabilities. This is particularly so, taking into account their greater risk of poverty and higher healthcare and rehabilitation needs.

Considering that disability is most common among older people, and that numbers of older people are rising globally due to population ageing, there is a need to increase the visibility of older people with disabilities in humanitarian action and promote their meaningful inclusion. This involves not just addressing their needs for assistance and protection, but also enabling them to participate in decision-making on issues that affect them, so that they can exercise their rights in full.



Phillip Sheppard/LSHTM

Recommendations

Drawing on these conclusions, we make the following recommendations to humanitarian donors, policy makers and practitioners.

1. Demonstrate leadership and institutional will

- Use the Humanitarian Inclusion Standards for Older People and People with Disabilities.
- Ensure that NGO senior staff take responsibility for including older people with disabilities in humanitarian work and are familiar with the relevant policy and legal frameworks and processes.
- Support humanitarian response work only where data that is fully disaggregated by sex, age and disability is used to plan, manage and monitor activities.
- Strengthen alliances between disability- and age-focused organisations.
- Fund humanitarian organisations to include older people and people with disabilities.

2. Strengthen evidence and data

- Routinely collect, analyse and use data on sex, age and disability throughout the programme, including looking in more detail at gender differences, and including data on mental health and cognitive impairment.
- Research the specific experiences and needs of older people with disabilities in more detail and in relation to specific issues, such as protection and opportunities for participation.

3. Promote participation and empowerment

- Recognise the rights and capabilities of older people with disabilities and include them in all stages of the response.
- Support older people, their families and carers to advocate for their rights and to understand the value of activity, rehabilitation and enabling environments.

4. Change attitudes and approaches

- Encourage humanitarian actors to hold themselves accountable for including older people with disabilities.
- Support humanitarian actors to better understand protection risks for older people with disabilities.
- Invest in activities to tackle age and disability discrimination and give older people with disabilities a stronger voice.

5. Put inclusion principles into practice

- Support older people's associations and disabled people's organisations to work together.
- Support non-specialist organisations to include older men and women at all stages of the response. Adapt guidelines, standards and training on age and disability inclusion to better address the intersection of sex, age and disability.
- Support welfare state departments to make social protection schemes accessible.
- Support healthcare providers to make health services accessible and provide the treatments and services needed.

Findings at a glance

This table brings together the findings from the different components of our research to show the needs, risks, barriers and enablers for older people with disabilities identified in the research.

Areas of concern	Increased risks	Barriers identified in research	Enablers identified in research
Livelihoods and social protection	Older people with disabilities are at increased risk of poverty. Our findings show they have higher healthcare needs and associated expenses, are less likely to work than older people without disabilities, and face barriers to participating in livelihood activities and accessing pensions.	<p>Physical: Distance to banks, lack of affordable transport, inaccessible buildings</p> <p>Institutional: Requiring displaced people to present themselves for verification purposes, denying disability pensions to those with a living relative, exclusion from livelihood programmes</p> <p>Attitudinal: Stigma associated with disability and pension distribution systems</p> <p>Financial: Lack of resources to start small businesses</p>	<p>Accessible pension distribution systems (for example, closer to home)</p> <p>Family support to access social pensions</p> <p>Accessible buildings</p>
Protection: Safety and evacuation from danger	Older people with disabilities may face greater difficulties evacuating, increasing risk of negative physical and psychological impact related to prolonged exposure to conflict, for example.	<p>Physical: Distance, terrain, lack of accessible evacuation routes</p> <p>Financial: Cost of accessible transport</p> <p>Information: Lack of accessible communication about disaster through TV or radio</p>	<p>Support from family</p> <p>Money for transport</p> <p>Proximity to border or contact line</p>
Healthcare and rehabilitation (medications, access to facilities)	Older people with disabilities have greater health and rehabilitation needs and are therefore disproportionately affected by costs and barriers to access these, contributing to worsening health, increased poverty and increased dependency on family.	<p>Financial: Direct and indirect costs of medication, other general health and impairment-specific interventions</p> <p>Physical: Inaccessible/unaffordable transport, stairs, nowhere to lie down, long queues</p> <p>Attitudinal: Negative attitudes of staff</p>	<p>Home visits, for example, by doctors and rehabilitation workers, community/social/incentive workers</p> <p>Proximity to health facilities</p> <p>Being given priority at health facilities</p> <p>Affordable/free transport</p> <p>Assistance from family members</p>
Access to food and other essential non-food items	<p>Older people with disabilities are at risk of exclusion from aid. Physical barriers to accessing distribution sites related to disability are likely to be exacerbated by ill-health and fatigue.</p> <p>Older people with disabilities are more likely to be poor, increasing their risk of food insecurity.</p>	<p>Physical: Distance, difficulty carrying rations, crowded distribution sites</p> <p>Institutional: For example, being required to be physically present, lack of priority being given, invisibility; closure of organisations providing humanitarian assistance</p> <p>Financial: Lack of financial resources to supplement food rations</p>	<p>Home visits (for example, community workers bringing food to people unable to leave their homes)</p> <p>Transport to distribution sites or family assisting with access to them</p> <p>Being given priority at food distribution sites</p>

Findings at a glance

Continued

Areas of concern	Increased risks	Barriers identified in research	Enablers identified in research
Accessible/ adapted shelter	Older people with disabilities are at greater risk of negative effects of basic and inaccessible shelter.	Physical: Inaccessible infrastructure (stairs, lack of ramps); inaccessible toilets; lack of household items (such as mattresses) Financial: Lack of resources to repair homes or pay for fuel to keep warm	Accessible infrastructure (such as ramps, rope to guide to toilet facilities) Fuel subsidies
Dignity	Older people with disabilities experience negative impact on dignity.	Physical: Lack of privacy in shelters, inaccessible latrines and houses Institutional: Inaccessible social pensions systems	
Independence, social interaction and participation	Older people with disabilities are more likely to face social isolation. They are less likely to participate in social activities outside the house.	Physical: Lack of transport, distance, inaccessible homes, toilets and public buildings, infrastructure destroyed by disaster; lack of assistive devices Attitudinal: Over-protection by families, lack of awareness of opportunities and rights for improved functioning and participation	Family and community Being visited by friends and community and social workers Proximity to social gatherings or assistance by family to reach them Belonging to and engaging with disabled people's organisations, religious groups, etc.
Protection from theft and discrimination	Older people with disabilities are at risk of discrimination based on age and disability. They are at risk of theft, especially those with reduced vision and hearing (Tanzania) or when collecting pensions (Ukraine).	Attitudinal: Negative attitudes among the community about rights to assistance and among state welfare departments who do not take their needs into account	Protection by family members Positive attitudes of community members
Psychological health	Older people with disabilities may be more vulnerable to poor mental health due to barriers to social participation, increased risk of poor health and pain, prolonged exposure to conflict, loss of previous role in family and loss of independence, and protection risks.	See barriers to social participation, evacuation, protection, livelihoods	Home visits by community workers See enablers to protection and independence, social interaction and participation

1. Introduction

Each year, millions of people are affected by humanitarian disasters. Among those most at risk are older people living with disabilities. Yet little is known about their particular experiences. Their rights, needs, participation and potential contributions are widely neglected in humanitarian response.

An estimated one billion people are living with a disability globally.¹ Disability is most common in older age groups and the number of older people with disabilities is increasing as the global population continues to age.

In 2016, 204 million people were affected by natural disasters and 65.6 million by conflict.² With 13 per cent of the world's population aged over 60 years,³ this means that up to 35 million older people may be affected by disasters, of whom more than one-third may be living with a disability.⁴

Older people with disabilities have the right to safe and dignified access to humanitarian assistance and protection without discrimination and on an equal basis with others. Yet they may face a range of barriers that prevent them from exercising their rights, including inaccessible infrastructure, stigma and discrimination, and high levels of poverty.⁵ In addition, older people with disabilities may require extra assistance, such as health and rehabilitation services.

Humanitarian programming, policy and guidance is focusing increasingly on the inclusion of older people and people with disabilities in humanitarian response. Tools are being developed to support this. For example, the Age and Disability Capacity Programme (ADCAP) recently produced a set of Humanitarian Inclusion Standards for Older People and People with Disabilities.⁶

Data on age and disability needs to be collected to develop inclusive humanitarian responses. The Sustainable Development Goals (SDGs), which pledge to “leave no one behind”, recognise that age and disability are important dimensions to disaggregate data by when countries report on progress towards achieving the SDGs.

However, the humanitarian sector is paying limited attention to the intersection of ageing and disability. There is little awareness of the particular experiences of older people with disabilities in humanitarian crises and how far their needs and rights are being met by existing humanitarian guidance and activities.

Aims and research questions

Our research aimed to address this evidence gap by investigating the specific experiences of older people with disabilities affected by humanitarian crises. It examined the barriers they face in accessing humanitarian assistance and protection, factors that enable their access, and the degree to which their needs are currently being met and their rights upheld.

This study helps to fill an important evidence gap on the intersection of older age and disability in humanitarian settings. To the best of our knowledge, this is the first study to specifically explore the experiences of older people with disabilities in a range of humanitarian settings.

We designed the research questions to explore the experiences and needs of older people with disabilities in humanitarian crises, and compared these with the experiences and needs of older people without disabilities. The specific research questions were:

- **Do older people with disabilities have additional needs and challenges accessing humanitarian assistance and protection?**
- **What factors facilitate or limit older people with disabilities' access to humanitarian assistance and protection?**
- **To what extent does humanitarian response address the needs and rights of older people with disabilities?**

2. Methodology

We used three complementary methods to address the research questions:

- A desk-based literature review to explore the experiences of older people with disabilities in humanitarian crises and find out how far they are included in the humanitarian response
- Quantitative data analysis of six population-based surveys comparing the living situation of older people with and without disabilities in different settings across the world
- Qualitative research with:
 - older people with disabilities and local key informants in two conflict-affected populations in refugee camps in Western Tanzania, and in Eastern Ukraine
 - global key informants from different selected humanitarian agencies.

The research was guided by three advisory committees, one in each research location (Tanzania and Ukraine) and one comprising experts in the ageing, disability and humanitarian sectors.

2.1 Literature review

We conducted a systematic literature review to identify studies that show how older people with disabilities are affected by humanitarian crises and how far they are included in corresponding humanitarian response. These included peer-reviewed journals and grey literature.⁷ We included observational qualitative and quantitative studies from any country, and studies from crises caused by conflict and natural disasters.

We did not include studies of resettled refugees in high-income countries, or studies that presented findings only on older people or people with disabilities (not explicitly on older people with disabilities).

We also reviewed key recent humanitarian guidelines available online to explore how far they explicitly address older people with disabilities.⁸

2.2 Quantitative study component

There is evidence that people with disabilities in low- and middle-income countries are more likely to be poor and face greater barriers to participating in key life areas such as education, healthcare and work than older people without disabilities.⁹ However, it is not clear whether this applies in humanitarian contexts.

To find out, we analysed six databases from population-based disability surveys, using comparable data collection methods. The data compared the living situation of people with and without disabilities in different parts of the world.

Very few surveys of disability have been undertaken in humanitarian settings. We found only two databases from low- and middle-income countries from crises-affected populations that contained data on disability. These were Haiti (post-earthquake) and Palestine.¹⁰ Given the scarcity of data available from humanitarian contexts, we also analysed data from four surveys undertaken in non-humanitarian settings. These were in India,¹¹ Cameroon,¹² Guatemala,¹³ and Nepal.¹⁴

About the survey datasets

The six datasets included people of all ages. We analysed data for people aged 60 years and above. The survey in Palestine was undertaken by the Palestinian Central Bureau of Statistics and the Ministry of Social Affairs. The other five surveys were conducted by the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine. All the surveys used standard sampling methods to identify representative study samples.

The disability surveys also included a “nested case-control study” to compare people with and without disabilities in key life areas. In all settings except Palestine, all people identified as having a disability through the survey were invited to participate (“cases”). For each person with a disability, one person of the same age, sex and location without a disability was also selected (“control”). Participants were interviewed about their socio-demographics status, work, education, health, participation restrictions and environment. In Palestine, all survey participants (all people with and without disabilities) were interviewed about socio-demographics, work and education. More details about these surveys are given in Appendix 1.

There are different ways of measuring disability (see Box: Measuring disability). Most disability surveys use the Washington Group questions.¹⁵ These ask how much difficulty a person has in different areas of functioning, for example, walking, seeing, hearing, cognition, self-care and communication. The surveys we analysed used both the Washington Group extended set of questions and the Washington Group short set of questions.¹⁶

The fact that disability is measured in different ways has implications for the reliability and validity of national prevalence findings on disability.

Measuring disability

Disability is complex and therefore challenging to measure. The World Health Organization (WHO) International Classification of Functioning conceptualises disability as a dynamic interaction between health conditions and contextual factors that are both personal (such as age, sex and education) and environmental (such as terrain, building design and laws).¹⁷

There are three main approaches to measuring disability that are compatible with this classification:

Direct questioning

For example, “Do you have a disability?” “Yes/No”. This approach is simple and quick. However, it is likely to underestimate the prevalence of disability, as people may not consider themselves to have a disability, or fear being stigmatised or discriminated against if they are labelled as disabled.

Assessments of impairments

Impairments are components of disability that can be measured using an objective assessment, such as testing visual acuity or level of hearing. Impairment data can inform planning of health and rehabilitative services. However, this approach does not consider how an impairment might affect a person’s level of functioning or participation in society.

Self-reported function

This approach asks people whether they experience difficulties in different functional

domains. The Washington Group on Disability Statistics has developed a short set of questions that aims to capture the proportion of the population living with different levels of functional limitation. The questions are about whether a person experiences difficulties in six basic functional domains: seeing, hearing, walking, cognition, communicating and self-care.

For example: “Do you have difficulty seeing, even if you are wearing glasses?” Response options include: “No, no difficulty”, “Yes, some difficulty”, “Yes, a lot of difficulty,” or “Cannot do at all”.

These questions are widely recommended for data collection on disability. They are simple and quick to use. They are suited to censuses and large-scale surveys where only a few questions can be included. They are not stigmatising as they do not ask about disability directly. However, they provide limited data on other key components of disability, such as participation restrictions or impairments. They also exclude certain important functional domains such as psychosocial functioning and mental health.

The Washington Group has also developed an extended set of up to 35 questions. These can be used in surveys where more time is available. The answers provide a more complete picture of a person’s disability. Additional domains include psychosocial functioning, pain, and upper body function. The extended set also includes more in-depth questions related to the basic domains of the short set, such as separate questions about near and distance vision.

Analysis of the survey data

We analysed the six datasets to estimate the prevalence of disability among people aged 60 and over, and to compare the living situations of older people with and without disabilities.

For the prevalence estimates, we only analysed data from three surveys (Cameroon, India and Guatemala). The other three surveys (Palestine, Haiti and Nepal) often relied on reporting by family members, which could lead to underestimates.

We used odds ratios to compare the socio-demographics, health, work and environment of older people with and without disabilities (see Appendix 2). We used linear regression to compare older people with and without disabilities in terms of their self-rated quality of life (data collected in Guatemala only) and restrictions on their ability to participate in society. All regression analyses were adjusted for age and sex as possible confounders.

2.3 Qualitative study component

The qualitative research included interviews with older people with disabilities, their families and other key informants in two crises-affected settings – Eastern Ukraine and refugee camps in Western Tanzania; and interviews with senior staff of five international agencies that have a role in humanitarian response.

Study settings

In Tanzania, we carried out research in Ndotu and Mtendeli refugee camps in Kigoma Region, Western Tanzania. Civil conflict and political instability in Burundi have led thousands of Burundian nationals to flee. More than 167,000 are currently living in these two refugee camps (see Section 3.4 for more details).

In Ukraine, we conducted the research in Donetsk and Luhansk provinces, Eastern Ukraine. These provinces have been affected by armed conflict since 2014 (see Section 3.5 for more details). Due to security concerns in non-governmental controlled areas of Eastern Ukraine, we collected data from government-controlled areas only.

In each country, we set up a local advisory committee to guide our research and help us interpret the findings. We consulted these committees on interview methods and questions to ask, and we presented preliminary findings to them to seek their feedback.

We chose these settings because they were relatively stable and safe for researchers to work in, as HelpAge International has offices in the area. Therefore, the research was conducted in two contrasting, protracted crises settings where HelpAge International operates.

Study participants

In both settings, we used HelpAge databases to identify older people with disabilities. We selected interviewees to reflect the experiences of men and women, different age groups and different types of disability. In Ukraine, we carried out research in areas where displaced people were living. We interviewed both displaced people and people already living there. In both settings, we also interviewed family members, if available at the time of the researcher's visit, to gain their perspective and acquire a broader picture of the needs, risks, barriers and enablers facing older people with disabilities.

In Tanzania, we interviewed 22 older people with disabilities and 11 family members. In Ukraine, we interviewed 31 older people with disabilities and five family members. The demographic and disability characteristics of the older people with disabilities are shown in Appendix 3.

In consultation with HelpAge offices, we identified 10 local key informants in each country in addition to the advisory committee members. They included representatives of local, national and international non-governmental organisations (NGOs), healthcare and rehabilitation providers, and local and national government.

Data collection

We used three different interview guides to collect information from older people with disabilities, family members and local key informants (see Appendixes 4, 5 and 6). We developed these guides with help from the international and local advisory groups. For interviews with older people, we also used the Washington Group short set of questions on functioning. We tested the interview guides with at least two interviewees in each setting.

In each setting, the interviews were conducted by two social researchers (one male, one female). They had each undergone four days' training. Interviews with older people and family members took place in their homes. Local key informants were interviewed at their place of employment or the HelpAge office. Interviews lasted on average 45 minutes and were conducted in the language spoken by the interviewees (KiSwahili or Kirundi in Tanzania, and Ukrainian or Russian in Ukraine).

Global key informants interviews

Semi-structured interviews were conducted with key informants from international organisations involved in humanitarian response to find out how far these organisations' policies, guidelines and response activities meet the needs of older people with disabilities. The international advisory committee proposed key informants to interview.

In total, five key informants of the ten invited agreed to be interviewed. They were senior staff from CBM, Humanity & Inclusion (formerly Handicap International), United Nations High Commissioner for Refugees (UNHCR), HelpAge International and International Federation of Red Cross and Red Crescent Societies (IFRC). The interviews were conducted by Skype using interview guides developed with the help of the advisory committee.

Qualitative data analysis

All interviews were audio-recorded, transcribed and translated into English. The findings were analysed by theme. Once all the data had been collected, we organised a preliminary analysis workshop with the researchers to identify themes and sub-themes. In each setting, we shared the preliminary analyses with six to eight older people with disabilities who had been interviewed and with the national advisory committee to obtain their feedback.

Ethical considerations

Ethical approval for our study was granted by the ethics committees of the London School of Hygiene & Tropical Medicine, Sociological Association of Ukraine and National Institute for Medical Research, Tanzania.

We obtained informed written consent from all interviewees, observed by an independent witness. For interviewees with intellectual impairments that severely limited their ability to understand or communicate, we sought a simplified oral assent. In these instances, we sought responses from the person concerned wherever possible and appropriate and obtained additional input from a family member where needed.

Section 2.4 Study limitations and strengths

Study limitations

For the quantitative analysis, we were only able to identify two datasets from humanitarian settings, neither of which contained data specific to the crises (such as data on access to humanitarian assistance). In the qualitative research, we did not include a comparison group (such as older people without disabilities). This limits our ability to disentangle needs and barriers specific to older people with disabilities from those that were common to older people in the two research settings.

The qualitative research was conducted only in populations affected by conflict. Information about other types of humanitarian crises, including natural disasters, is therefore limited to findings from the small number of studies identified in the literature review, the two quantitative datasets and the perspectives of global key informants.

The research was undertaken in settings where HelpAge International is operating. The findings may not be generalisable to settings where HelpAge International is not working, and where older people with disabilities may therefore be more neglected. Further, although the interviewers were not HelpAge employees, interviewees were informed that the research was being undertaken with HelpAge International. This may have introduced social desirability bias (interviewees answering in a way to please the interviewer).

Finally, the research questions were broad. These enabled us to take an important first step to building comprehensive empirical evidence of the situation for older people with disabilities but limited in-depth exploration of particular issues.

Study strengths

To the best of our knowledge, this was the first study to specifically explore the experiences of older people with disabilities in a range of humanitarian settings. This study helps to fill an important evidence gap on the intersection of older age and disability in humanitarian settings. We used different complementary research methods to generate comprehensive evidence. Through the three advisory committees, we engaged widely with international experts to conduct the research.



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3. Study findings

3.1 Findings from the literature review

Key findings

Few studies focus specifically on older people with disabilities in humanitarian contexts, particularly in low- and middle-income countries. Studies that are available focus broadly on either ageing or disability and include limited findings specific to older people with disabilities. The limited research available indicates that older people with disabilities in humanitarian contexts are a neglected group.

The review of research studies and humanitarian guidelines suggests that:

- Older people with disabilities have more difficulty escaping from conflict or natural disasters and accessing humanitarian assistance than older people without disabilities because of environmental and other barriers.
- Older people with sensory or cognitive impairments find that information is not available to them.
- Older people with disabilities are more affected psychologically by humanitarian crises. Mental health and existing cognitive impairments are worsened, although the reasons for this are not well explored.
- Humanitarian guidance and standards contain recommendations on the needs and risks faced by older people and people with disabilities, but provide no specific analysis and guidance on older people with disabilities.

Selection of studies

We identified 2,219 studies with search terms that suggested they might contain information on older people with disabilities in humanitarian crises. Of these, we excluded 2,208 because they did not include this information. Four articles could not be found. We identified an additional seven studies in the grey literature.

The survey highlighted the lack of research on the intersection of older age and disability in humanitarian contexts. Only 14 studies included findings on the experiences of older people with disabilities in humanitarian contexts (see Appendix 7). However, the majority of these studies (10) focused broadly on either ageing or disability and included limited findings specific to older people with disabilities.

Eight of the 14 studies were from low- and middle-income countries. They all focused on conflict-affected populations, except one study from Nepal post-earthquake. The six studies from high-income countries all focused on natural disasters. We did not identify any studies that specifically compared the experiences of older people with and without disabilities.

In terms of disability type, five of the 14 studies focused on specific impairments – four on intellectual impairments and one on visual impairments. The other nine studies covered all disability types.

Six of the 14 studies used quantitative methods, five used qualitative methods and three used both approaches. Most of the study reports and some peer-reviewed papers lacked details of methodology, making it difficult to assess the quality.

Breakdown of the studies

Total numbers

- 2,219 studies reviewed
- 2,129 excluded during title and abstract review because they did not include any information on older people with disabilities in humanitarian crises
- 79 excluded following full text review
- 4 articles could not be found
- 14 yielding findings on the experiences of older people with disabilities in humanitarian contexts

Settings and crises types

- 8 from low- and middle-income countries:
 - 7 focusing on conflict-affected populations
 - 1 focusing on natural disaster
- 6 from high-income countries:
 - all focusing on natural disasters

Topics of focus

- 10 focusing on either ageing or disability (but including some information on older people with disabilities)
- 4 focusing specifically on older people with disabilities (all in high-income countries)
- None specifically comparing the experiences of older people with and without disabilities

Disability types

- 5 focusing on specific impairments
- 9 covering all disability types

Survey methods

- 6 using quantitative methods
- 5 using qualitative methods
- 3 using both approaches

Experiences of older people with disabilities

The points to emerge most strongly from the studies were that older people with disabilities found it harder to escape from a disaster, and faced more barriers to obtaining information and accessing services than older people without disabilities.

Difficulty escaping

Four studies provided some limited findings on evacuation during emergencies. Research in Japan¹⁸ found that, during an earthquake and tsunami, environmental barriers such as steps, lack of handrails and uneven pavements, and lack of assistance made it difficult for older people with mobility impairments to escape. In the USA, research suggested that older age and dementia were associated with being less likely to evacuate.¹⁹ Disability was given as a reason for older people to stay behind when other family members fled from conflict in Syria²⁰ and Ethiopia²¹ although the reasons for this were not explored.

Difficulty obtaining information

Two studies from high-income countries highlighted difficulties that older people with disabilities had with accessing information during earthquakes. Channels such as radio and television were difficult to use by older people with a visual impairment in New Zealand²² and older people with a mild cognitive impairment in Japan.²³

Difficulty accessing services

Seven studies highlighted difficulties in accessing services, both post-disaster and in refugee camps. The destruction of infrastructure after an earthquake in New Zealand prevented older people with visual impairments from reaching health services, leading to poorer health and increasing social isolation.²⁴ Three research reports by NGOs in Nepal post-earthquake, among Syrian refugees in Lebanon and in displaced people's camps in Darfur, Sudan, suggested that older people with disabilities faced physical barriers to reaching health services²⁵ and food²⁶ and aid distribution sites.^{27, 28} Long queues and busy crowds got in their way.^{29, 30, 31}

Research by UNHCR in Ukraine found that state services supported single older people with disabilities who had no children, but not those with children. This may make older people with disabilities more vulnerable and force them to become more dependent on their families.³² Research on access to specialist services is very limited. Interviews with older displaced people in Uganda and Pakistan, many of whom had eyesight problems, suggested that, although good eyecare facilities existed nearby, many older people were unaware of them or unable to reach them.³³

Difficulty with daily activities

Information on how well older people with disabilities could carry out daily activities was also very limited. Among displaced populations in Uganda and Pakistan, it was reported that older people with mobility problems could not farm, when they had previously relied on farming to feed themselves.³⁴

Greater trauma

There was some evidence that humanitarian crises have a greater psychological impact on older people with disabilities. A study in Nepal³⁵ post-earthquake suggested that older people with disabilities felt significantly more traumatised, anxious and depressed than older people without disabilities. Research by the Women's Refugee Commission in Ecuador, Jordan, Nepal, Thailand and Yemen suggested that displaced older people with disabilities were particularly likely to feel isolated and lose status in their family or community.³⁶

Lack of specific guidance

In terms of key humanitarian guidelines available online, there is very little information or guidance specifically addressing the needs and risks faced by older people with disabilities. The study of key humanitarian guidelines available online showed an understanding of the need to include older people and people with disabilities in humanitarian response, to collect data disaggregated by sex, age and disability, and to be aware of the intersectionality of sex, age and disability.

Some of the key mainstream humanitarian sector guidelines, such as the Sphere Handbook³⁷ and Core Humanitarian Standards,³⁸ emphasise the need to include older people and people with disabilities and collect data on older people and people with disabilities.

In terms of disability-focused guidelines, the Charter on Inclusion of Persons with Disabilities in Humanitarian Action³⁹ emphasises the need to consider the intersection of disability and other characteristics, including age, and states the importance of disaggregating disability data by age. *All Under One Roof*⁴⁰ briefly mentions the need to link disability with other cross-cutting issues, including age. The Humanitarian Inclusion Standards for Older People and People with Disabilities provide guidance on including older people and people with disabilities and refer to the intersection of age and disability.⁴¹ The WHO *World Report on Ageing and Health*⁴² briefly highlights the impact of mobility restrictions on evacuation and access to services.

3.2 Findings from the quantitative data analyses

Key findings

We analysed six disability survey datasets to estimate the prevalence of disability in older people, and compare the needs of older people with disabilities with those of older people without disabilities in low- and middle-income countries. The findings revealed a high prevalence of disability and greater participation restrictions for older people with disabilities:

- Disability was common among older people. The proportion of people aged 60 and over living with a disability ranged from 22 per cent in Guatemala to 39 per cent in India. Disability increased with age: the proportion of people aged 80 and over living with a disability ranging from 39 per cent in Cameroon to 66 per cent in India.
- Using these findings, we estimate that between 7.8 million and 13.7 million older people with disabilities are affected by humanitarian crises. In all settings, the functional domains that older people most commonly reported having significant difficulty with were mobility and vision.
- Compared with older people without disabilities, older people with disabilities were significantly:
 - less likely to have worked in the past week or past year
 - more likely to have experienced a serious health problem in the past year
 - more likely to have had difficulty understanding information provided at health facilities
 - more likely to have spent more than a quarter of their income on healthcare
 - more likely to be restricted in how much they could take care of themselves, carry out domestic activities, interact with other people, work and take part in community life
 - more likely to have been prevented from taking part in activities that mattered to them
 - more likely to rate their quality of life as poor.

There is a connection between people's health and financial status and their capacity to survive a humanitarian crisis. People with money and good health are better placed to escape the disaster and live elsewhere than people with little money and poor health, who are more vulnerable to public health risks such as outbreaks of disease.

Prevalence of disability in older people

The analysis of three datasets to estimate prevalence of disability among people aged 60 years and over showed that disability prevalence ranged from 22 per cent in Guatemala to 39 per cent in India (see Appendix 8).

Prevalence increased significantly with age, so that between 39 per cent of people aged 80 years and over in Cameroon and 66 per cent in India were living with a disability. In India, the prevalence of disability was significantly higher among women than men. However, this difference was not evident in Guatemala or Cameroon. The wide range of prevalence estimates may, in part, reflect the challenges of measuring disability.

We can use the prevalence of disability from these different settings to estimate the number of older people with disabilities affected by humanitarian crises. If we assume that 204 million people are affected by natural disasters and 65.6 million are affected by conflict,⁴³ 13 per cent of world's population is aged 60 years,⁴⁴ and 22-39 per cent of older people are living with a disability, this means that 7.8-13.7 million older people with disabilities may be affected by humanitarian crises.

In all four countries, mobility and eyesight were the functions that older people most commonly said they had a significant problem with. For full details of findings, see Appendix 8.

Comparison of older people with and without disabilities

The comparison between older people with and without disabilities suggested that older people with disabilities had a similar socio-economic status, but did less work, had poorer health and had a lower quality of life than older people without disabilities. A table of comparing the demographic and economic characteristics of older people with and without disabilities is given in Appendix 9. $P < 0.05$ was used as the cut-off value for statistical significance.

Similar socio-economic status

In Palestine, older people with disabilities were significantly less likely to have had any formal education than older people without disabilities. They were more likely not to be literate. However, this difference was not found in any of the other settings.

There was no evidence of any difference in the socio-economic status of households with older people either with or without disabilities. This finding may reflect the high levels of poverty in all the study settings, making it difficult to detect any differences. Further, only asset-based economic measures were used in these studies, rather than more multi-dimensional measures of poverty, such as health, work, education and food security that might be more affected by disability status.

Less likely to work

In all six countries, older people with disabilities were significantly less likely to have worked either in the past week or past year than older people without disabilities (Figure 1). For example, in Guatemala, only 18 per cent of older people with disabilities had worked in the past week, compared with 44 per cent of older people without disabilities. In Haiti, 11 per cent of older people with disabilities had worked, compared with 34 per cent of older people without disabilities.

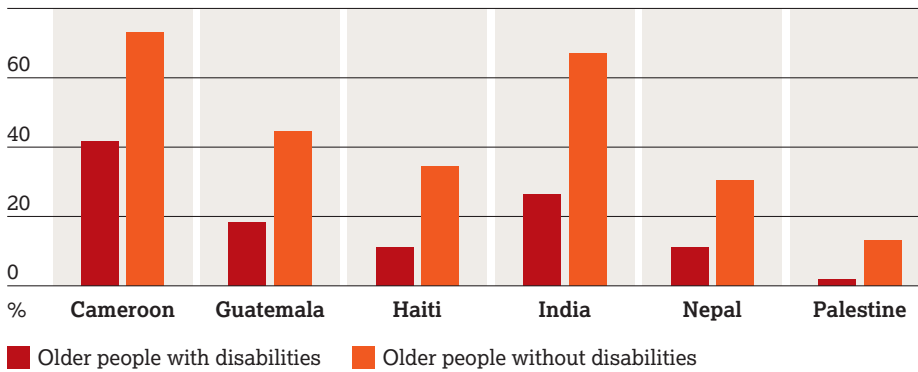
Marked variations in the proportions of older people working in different countries are likely to be due to different definitions of work used in the different studies. For example, the studies in India and Cameroon included working on land owned or rented by the household, but other studies did not include this.

More health problems

Older people with disabilities were more likely to report having a serious health problem in the past year than older people without disabilities in the four countries where this data was collected (Figure 2). In Guatemala, older people with disabilities were four times more likely than older people without disabilities to say they found it difficult to understand the information they were given at health facilities.

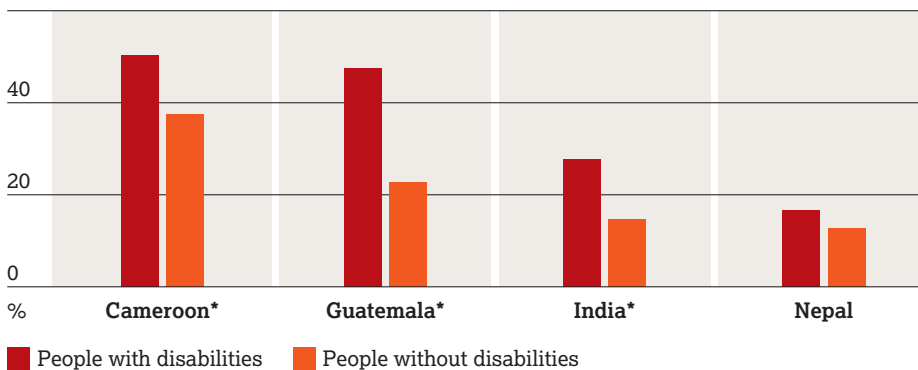
In Nepal, data on household expenditure and income were also collected. This showed that households in which an older person with a disability was living were twice as likely to have spent more than a quarter of their income on healthcare (the amount considered by WHO as putting households at high risk of healthcare spending-induced poverty).

Figure 1: Proportion of older people with and without disabilities who had worked in the past week



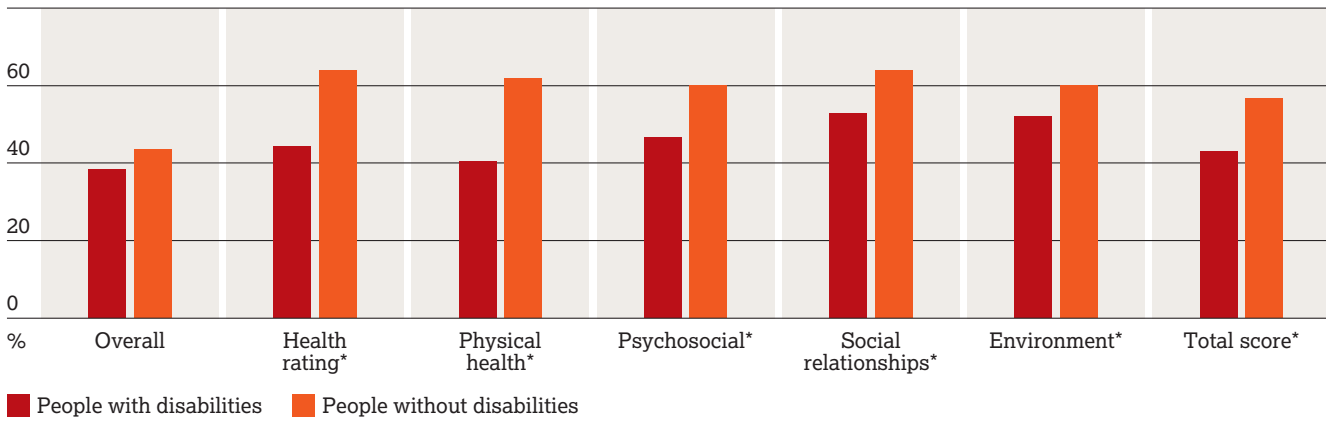
The difference was statistically significant in each setting.

Figure 2: Proportion of older people who reported a serious health problem in the past 12 months



*Statistically significant difference between older people with and without disabilities (this data was not collected in Haiti or Palestine)

Figure 3: Self-rated quality of life among older adults with and without disabilities



Note: Higher score denotes better quality of life.

*Statistically significant difference between people with and without disabilities

Poorer quality of life

In Guatemala, older people were also asked to rate their quality of life, using the WHO Quality of life-BREF instrument.⁴⁵ Older people with disabilities rated their quality of life significantly lower than older people without disabilities, both overall and in each sub-scale (see Figure 3).

Less able to participate

In Guatemala, India, Cameroon and Haiti, survey participants were asked about the level of difficulty they had with performing a range of activities in their current environment (for example, with the assistance of any person, if they received this, or assistive devices if they used them). Each question was scored on a four-point response scale; “no difficulty”, “moderate difficulty”, “severe difficulty” and “inability to perform”. Older people with disabilities reported significantly greater difficulty than older people without disabilities with carrying out domestic activities, interacting with other people, working or taking part in community life. Details are given in Appendix 10.

When asked to identify environmental barriers that prevented them from participating in activities that mattered to them, older people with disabilities were more likely than older people without disabilities to report these areas as being a “big problem” – though the difference was not always statistically significant, reflecting in part the low numbers included.

Details are given in Appendix 11.

3.3 Findings from global key informants interviews

Key findings

Findings from interviews with representatives of five international organisations that deliver humanitarian assistance – CBM, HelpAge International, Humanity & Inclusion, IFRC and UNHCR – showed that, although their organisations aimed to address the needs and rights of older people with disabilities, they were concerned that older people with disabilities risked being missed in these efforts. They highlighted a disconnect between age-focused organisations and disability-focused organisations, both locally and globally.

Policies and guidelines

Representatives of international organisations highlighted a number of policies and guidelines promoting age and disability inclusion. UNHCR has an Age, Gender and Diversity Policy as well as guidance on working with people with disabilities. Other documents mentioned were the Core Humanitarian Standards, Humanitarian Inclusion Standards for Older People and People with Disabilities, the Sustainable Development Goals, Sphere Handbook, Disability Charter, CBM’s Disability Inclusive Development Toolkit and *All Under One Roof*.

All the interviewees said that their organisations were trying to mainstream disability, age and gender in all of their humanitarian response programmes. HelpAge International specifically aims to “broaden the lens” of its work to ensure that older people with disabilities are better recognised and included in all its activities.

The other four organisations do not have any activities or guidelines specifically for older people with disabilities, but aim to be inclusive of age and disability in all their work. Organisations with a disability focus aim to be inclusive of older people as part of their broader inclusion agenda.

Despite these aims, interviewees felt that the needs of older people with disabilities were not being well met in humanitarian crises. While there is some focus on disability and, to a lesser extent, older people, older people with disabilities are often “invisible”. Older age and disability are not often considered together.

Areas for attention

Key areas for attention were the disconnect between organisations focused on age and disability, the intersectionality of age and disability, efforts to be inclusive and participatory, and collecting data on age and disability.

Disconnect between age and disability

Humanitarian guidelines are increasingly promoting age and disability inclusion. The new Humanitarian Inclusion Standards for Older People and People with Disabilities documents key actions and guidance for including older people and people with disabilities in humanitarian responses. However, interviewees were still concerned that older people with disabilities risked being missed in these efforts.

Some highlighted a disconnect between organisations focused on the rights of people with disabilities and those focused on ageing. They said that older people were left out of efforts towards disability inclusion and vice versa. This was happening at the local as well as global level, for example between local older people’s associations and disabled persons’ organisations.

Lack of attention to intersectionality

Representatives of international organisations pointed out that little attention was being given to the intersection of age and disability. Even when agencies (either generalist or specialist) aimed to be inclusive in their humanitarian approach, they did not consider older age and disability together. Some interviewees said there was a need to examine intersectionality of disability, age and gender to understand differing needs for humanitarian assistance. For example, many of the needs of an older woman with a disability would differ substantially from those of a younger man with a disability.

Limited efforts to be inclusive

International organisation representatives said that although it was important to mainstream age and disability, this could be difficult to do in practice. Although they felt that all organisations should do this, in reality, non-specialist organisations often

relied on disability or age-focused agencies to deliver initiatives targeted at people with disabilities or older people. One interviewee explained that their organisation was very aware of the link between disability and ageing and tried where possible to address the needs of older people, but they were limited because their primary focus was on disability.

The level of support from senior management emerged as another influencing factor. Some interviewees felt that senior management supported their work on age and disability. However, others felt there was a lack of support that created a barrier to progress towards adopting a more inclusive approach. Two interviewees said that they had previously worked for organisations that had removed their disability inclusion position because they did not see its value. One interviewee said that despite broad support in their organisation for an inclusive approach, there was a lack of understanding of the resources, expertise and strategy required to drive this forward. Another interviewee argued that inclusion should only be considered as having been achieved when people with disabilities and older people were included in all their meetings, planning and project development related to those specific groups, which was currently not happening.

Challenges to being participatory

All the representatives of international organisations said that a participatory approach was important. This means, for example, including older people with disabilities in all aspects of planning, developing, implementing and monitoring programmes. They said their organisations took a participatory approach to project development.

Although they acknowledged the unique role of older people and people with disabilities and the importance of including them in planning humanitarian responses, they highlighted challenges to achieving this. One interviewee was concerned that they had attended meetings to develop humanitarian programmes and standards for people with disabilities at which no people with disabilities were present. They commented that if organisations that were creating such standards could not be inclusive, it would be extremely difficult for other non-specialist organisations to deliver programmes to people of all ages and abilities.

The interviews suggested that change agents could be driving forces for the creation of inclusive programmes and participatory approaches. For example, one interviewee said they had personally taken the initiative to include a person with a disability in the training they were conducting. Another highlighted their push to include older people where possible, although the organisation’s specific focus was on disability.



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Mixed approaches to data collection

There was consensus among all the representatives of international organisations that data on age and disability needed to be collected and reported, using consistent tools and standards. Interviewees from organisations that were doing this described the methods used.

HelpAge International collects and disaggregates data on age, sex and disability, using this to develop its humanitarian responses and advocate for other organisations to do the same. The main tool used for disability assessment is the Washington Group questions (described on page 12). As part of its Disability Statistics in Humanitarian Action project, Humanity & Inclusion is testing the Washington Group questions for use in humanitarian contexts and developing guidance for other humanitarian actors on how to use these.⁴⁶

Another interviewee commented that organisations that start collecting data disaggregated by age, sex and disability quickly recognise the benefits of having more information about the groups they are working with, leading to improvements in practice. However, not all the organisations represented are using the Washington Group questions. Some are using questions specific to their organisations. Some interviewees said they were concerned that the Washington Group questions do not apply to everyone who has a disability.

One interviewee remarked that it was difficult to include these questions in needs assessments, considering the thousands of refugees that need to be processed in some humanitarian settings.

Current training initiatives

The representatives of international organisations highlighted several current staff training initiatives to promote age and disability inclusion. These typically focused either on disability inclusion, or on people with disabilities and older people, but did not give specific consideration to the intersection of disability and ageing.

For example, UNHCR is developing an e-learning module on working with people with disabilities. The International Federation of Red Cross and Red Crescent Societies (IFRC) has developed a training programme that provides guidelines, minimum standards and basic information about how to identify and fight discrimination and ensure the highest level of integrity. HelpAge International is developing induction training for all staff which includes working with older people and people with disabilities. Humanity & Inclusion runs training and coaching to support its own staff and staff of other organisations to be more inclusive.



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3.4 Findings from interviews in Tanzania

The situation in Tanzania

Civil conflict and political instability in Burundi have resulted in more than 300,000 Burundian nationals fleeing to neighbouring countries, primarily to Tanzania. More than 165,000 Burundian refugees are living in Nduta and Mtendeli refugee camps in Kigoma Region, Western Tanzania.

“People with specific needs” (the term used by UNHCR) are identified by UNHCR when refugees arrive at the camps. They include girls and boys at risk, people with serious health conditions, people with special legal or physical protection needs, single women, women-headed households, older people, people with disabilities and people who may be discriminated against because of their sexual orientation or gender identity. UNHCR collects data on the age and disability status of people entering the camps (although not using the Washington Group questions).

UNHCR aims to include services for people with specific needs in all its initiatives in the camps. It also aims to partner with organisations that have a particular focus on one or more of these groups. In Nduta and Mtendeli camps, UNHCR refers all older people and people with disabilities to HelpAge International.

HelpAge International is the only organisation working specifically with older people and people with disabilities within Nduta and Mtendeli camps. HelpAge provides direct support, such as distributing non-food items, providing transport, distributing assistive devices and providing psychosocial support. It arranges for incentive workers (refugees receiving an “incentive” payment to support the work of humanitarian agencies) to visit different zones of the camps to assist older people and people with disabilities. HelpAge has set up “multi-purpose safe and inclusion spaces” in the camps to provide social opportunities and information for older people and people with disabilities. HelpAge also advocates for other agencies to include older people and people with disabilities in their work.

Hospitals in the camps are coordinated by Médecins Sans Frontières (MSF) in Nduta and Tanzania Red Cross in Mtendeli. Both camps have one main hospital. MSF also has a team of social workers and a mobile medical team who provide services (such as delivery of medication) to people with disabilities. If a refugee needs a health service that cannot be provided in the camp, there is a referral system through which they may be sent to the nearest hospital in the community.

Key findings

Interviews with older people with disabilities, family members and key informants from the refugee camps showed that older people with disabilities had had difficulties escaping the conflict in Burundi. Living conditions in the camps were poor and toilets inaccessible. Some older people with disabilities were worried about security. Some said they had been discriminated against.

Some older people with disabilities faced difficulties collecting food and other items themselves. Restrictive systems, such as the requirement to go to distribution points in person, prevented some from receiving aid. As a result, some said they did not have enough food and went hungry.

Most interviewees said they could access health services in the camp when they needed to. The main problems were a lack of medication to treat their condition and being prescribed treatment they perceived to be ineffective.

Too little social participation was a problem for many interviewees. Many also said they would have liked to work but had no opportunity. Their experiences contributed to poor mental health. Family support and social activities were particularly important for their wellbeing.

More risk escaping from danger

Some older people with disabilities, particularly those with physical disabilities, said they had found it difficult to escape from the conflict in Burundi. Because of this, they were more at risk of being caught in gunfire surrounding them. Some had had to wait and hide:

“There were helicopters flying above and shooting down. I stayed in a hole for three days without any food or drinking water.” Female, 70

Many interviewees said they had relied on their family and friends to help them reach the camps. Family and friends had provided both physical and financial assistance, for example, paying for transport:

“She couldn’t walk quickly from the place where we were. So, as her child, I paid her fare so she could use transport to reach the camp safely. As for me, I came here on foot.” Family member

The threat facing those unable to escape and the value of family support is reflected in the experience of a woman with a physical disability who could not afford to pay for transport:

“I told them to leave me in the bush and continue to the secure area without me. They just cried. They told me that the strategy used to find people was to set fire to the forests. They said ‘Don’t you see that you could burn?’ They decided to bring me to this secure area.” Female, 62

Some older people with disabilities had had less difficulty fleeing. This appeared to be related to factors such as living close to the border and having money for transport.

Poor living conditions and inaccessible toilets

Refugees in Mtendeli and Nduta camps live in houses made of tarpaulin or locally made brick or mud. These houses are generally very small and often crowded. The interviews suggested that older people with disabilities who were unable to leave their house independently suffered from the lack of privacy and loss of dignity:

“I have no privacy. Living in the same house as my grown-up children isn’t good at all.” Male, 62

Some older people said they had been given mattresses and blankets, but others said they had not received these. Although living conditions are poor for everyone in the camps, some older people with disabilities seem to be living in particularly poor conditions because they have difficulty maintaining their houses. Further, sleeping on a rough floor is particularly hard on older people with disabilities. It can exacerbate existing physical and health conditions:

“This house isn’t good for me because I am disabled. I can’t fix it to be in good shape like the others. I sleep on the floor. I don’t even have a mattress. My back always hurts when I wake up. I don’t have any energy.” Male, 65

Inaccessible toilets were a serious problem. Several interviewees said they could not reach the toilets on their own, or had difficulty using them. The interviews suggested that this deprived them of their independence and dignity. Family members said that helping their relative use the toilet also left them with less time for other activities. In one case, a family member said that the problems her mother had with using the inaccessible toilet had led to conflict with neighbours. The neighbours complained that her mother left the shared toilet “dirty” because she could not see well.

One family member highlighted the profound effect a simple, low-cost intervention could have:

“She can’t go to the toilet without some help. We ask you to follow up so that they provide a specially designed toilet near the house and put up a rope to direct her to it. This will help her if there is nobody around. We did this at home in Burundi. She went to the toilet by herself. It would also free me up to earn some money to buy her medicine. If I don’t buy it, I have to ask friends to help me. It’s becoming a problem.” Family member

Some older people with disabilities said they were worried about security. In particular, they felt more at risk of theft – for example, of tarpaulins, kitchen utensils, food, blankets and mattresses. Older people with poor eyesight felt particularly at risk. One older woman had had food stolen from her. Another had been robbed of her kitchen utensils:

“I can’t tell if it’s safe here or not. The kitchen utensils that I was given were stolen when we were still in the main tent. My children weren’t around and I can’t see.” Female, 62

Discrimination and unequal distributions

Some interviewees said they were shown respect by other refugees and agency staff. They said they were treated “the same as others”. However, others said they had been discriminated against because of their age and disability. Some said younger people had told them they should leave the camp. They accused them of faking poor health to obtain money:

“They say we’re pretending to be sick so that we can get a lot of money. If they see us going to the HelpAge office, they think we’re being given a lot of money.” Female, 70

All the older people with disabilities that we interviewed were registered with HelpAge International. HelpAge was the agency they mentioned most often in relation to providing or facilitating access to humanitarian assistance in the camps. Interviewees commonly mentioned receiving household items (such as mattresses, soap, buckets and blankets), mobility devices and rehabilitation. It emerged that they particularly valued incentive workers, who visit different zones of the camp to assist older people. For example, they provide information (such as details of services in the camps) and facilitate access to healthcare:

“We normally receive accurate information about how to access services in the camp from our incentive workers. They pass through our zone announcing what services we should receive.” Female, 100

However, a few interviewees said they had not received humanitarian assistance on an equal basis with others:

“To begin with, he was only given a mattress, while other people were given a mattress plus other items such as a blanket.” Family member

Physical barriers to collecting food

The things older people with disabilities said they needed most were food, money, clothes, mattresses and blankets. Lack of food was a common concern among older people with disabilities. Some said they often went hungry. Key informants said agencies

were trying to improve their access to food by transporting them to the distribution sites and giving them priority during food distributions. Accordingly, most of those interviewed said they did not have any particular difficulty collecting their food rations.

However, some were at risk of missing out. A few of the interviewees suggested they faced physical barriers to reaching the food distribution sites and bringing their food rations back home:

“It’s difficult for me to carry my food ration because of my poor health and my disabilities.” Female, 100

Interviewees also pointed out that it was difficult for older people with disabilities to collect their food rations when the distribution sites were so crowded:

“Since most of the people at the distribution sites are young, we have to fight to collect our food which an older person can’t do.” Family member

Interviewees also talked of physical barriers to reaching social and rehabilitation services for older people:

“Her legs don’t let her to go to the place where older people meet. She’s only managed to go there twice.”

Restrictive systems for claiming assistance

Systems also presented barriers to accessing assistance. Two interviewees said that, although they were aged over 60 years, their names were not on the “elders list”, and this prevented them from receiving aid that other people over 60 had received.

In addition, the interviews suggested that the requirement for people to go in person to distribution points meant that some were denied their right to receive humanitarian aid. For example, people are expected to collect food rations themselves to limit the risk of food theft. This makes it difficult for family members or friends to collect food on behalf of people who cannot reach the food distribution sites:

“When I try to collect her portion they always tell me that I’m going to steal the food. They refuse to give me her portion.” Family member

The situation is similar with clothes:

“He wasn’t given any clothes because he had to go there himself. He can’t get out of the house so he can’t get his share.” Family member

Staff of humanitarian agencies said they were doing their best to identify people with specific needs and give them priority at food distributions by organising special queues. However, they acknowledged that some older people with disabilities might be unaware of the priority queues and not being directed to them. This shows that although systems are in place, they do not always work in practice.

Inadequate food and hunger

Another problem with food rations was that there was too little food or it was not varied enough. Some older people with disabilities said that other people in the camps could trade money or goods for extra food, but this was not an option for them because they did not have enough money. They had to go without any food between distributions. Their diet was lacking in variety and in fresh produce:

“I’ve had enough of ugali [maize porridge] and beans. They’re giving me a hard time. The young ones just eat what they want without any problem but I can’t. What I like to eat is bananas, cassava, sweet potatoes and maybe beans.” Male, 65

Lack of food caused physical and emotional distress:

“We just sit. We haven’t had anything to eat since yesterday. We’re waiting for another food ration. Sometimes I cry and tighten a rope around my stomach and sleep on my stomach because I’m so hungry.” Female, 62

Shortage of drugs and uneven rehabilitation services

Most interviewees said they could access health services in the camp when they needed to. These are provided for free. An attempt is made to locate older people and people with disabilities closer to health centres. This emerged as important for enabling them to access the services. However, it is often not possible to do this because of the limited availability of housing and large geographical area of the camps. Nearly all the older people with disabilities we interviewed said they relied on family members or neighbours to help them reach health services, either by walking with them or by arranging transport.

The main problems that older people with disabilities faced were a lack of medication to treat their condition and being prescribed treatment they perceived to be ineffective. Some interviewees said they had been prescribed medication that either did not help their condition or was not available in the camp:

“I went to the doctor. He recommended me to take some medicine. But the person providing the medicine claimed that the drugs the doctor had recommended are not available here.” Female, 100

Given that older people with disabilities are more likely to have serious health problems than the general population, the shortage of medicines could affect them particularly profoundly. For example, they are likely to be particularly affected by non-communicable diseases.

Interviewees had mixed experiences of the attitudes of health providers towards them. Some said they were treated well or given “higher priority”, such as going to the front of the queue at health facilities.

Preferential treatment seemed to be given to people with visible disabilities, such as those using a mobility device. However, this was not uniform. Others said they had received poor treatment or been discriminated against:

“It’s a disaster. They don’t acknowledge me when I get to the hospital. I can spend the whole day waiting because I’m disabled.” Male, 65

Several older people with physical disabilities spoke positively about the rehabilitation services provided. They said they had been given walking sticks and received rehabilitation at home. However, a few said they had not received the interventions they needed, such as a wheelchair. This appeared to apply particularly to older people with vision problems:

“When we arrived here, we were informed that we could get treatment for our eyes. But nothing has happened so far.” Female, 102

Social isolation and loneliness

Too little social participation was a problem for many interviewees, particularly those with severe functional limitations or ill-health. Some described just sitting all day without having anyone to talk to:

“I just sit there in front of my house. When I get tired, I go to sleep.” Female, 102

Some older people with disabilities said it was harder for them to visit friends and take part in social or religious activities, or attend meetings about running the camp than older people without disabilities. The main reasons they gave were that they were physically unable to reach these gatherings, long distances or they felt too tired:

“When meetings are held a long way from here I don’t go because I don’t have enough energy to walk there.” Male, 80

Religion was evidently important to some of the people we interviewed. Being unable to go to church and pray with other people was a recurrent concern. It seemed to contribute to loneliness and poorer mental health.

Being visited by friends, having good health, living near sites where events were held or being assisted by family members to reach these, were factors that enabled older people with disabilities to participate in society. Participation had benefits for their mental wellbeing, sense of belonging and happiness:

“When she has the energy, she can use her walking stick to go and worship. She can talk to other people. She can be happy.” Family member

No opportunity to work

With no state pension available, another common concern among older people with disabilities was having no opportunity to work. Many were extremely poor. There are limited opportunities for residents of the camps to work, particularly as they are restricted from travelling outside the camp into neighbouring communities. Younger people and people without disabilities may find work with NGOs, or set up small businesses such as shops and market stalls. Older people with disabilities felt they did not have the same opportunities.

This point was also evident in local key informants interviews. One NGO supports refugees to earn an income (for example, by providing business training, gardening training and support to savings groups) but focus primarily on younger adults. Several older people with disabilities who had farmed in Burundi said that because of their disability, poor health or displacement, they could no longer farm:

*“I can’t carry out any kind of agricultural activities now because of my age and poor state of health.”
Female, 82*

Several interviewees spoke of the negative social, financial and emotional impact of losing the opportunity to work:

*“I feel sad that I can’t do the things I did before. I used to cultivate some land and be independent, but I can’t do that now. I used to have visitors and manage to give them something, but not any more. I can’t do anything. This upsets me a lot.”
Female, 90*

Many of the older people with disabilities we interviewed said they wanted to earn an income. They said that if they could receive some financial support, they would start a business at home or nearby, such as selling goods:

*“I need capital, so that I can set up a business such as selling some materials while I sit at home.”
Male, 62*

Earning an income and contributing to their families would enhance their sense of self-worth, but they were limited by lack of money, lack of opportunity to be more independent, and lack of work opportunities.

Importance of family and neighbours

Family and neighbours clearly contribute substantially to the physical and psychological wellbeing of older people with disabilities in the camps. For example, they assist them with daily activities, help them obtain services and provide companionship. Family members commonly expressed compassion for their relatives and accepted their caring role:

“We live with him because he’s our father. We can’t leave him. Most of all, we just love him and give him what we can.” Family member

However, some family members said that caring for an older relative meant they had less time to work and socialise, affecting them financially and emotionally. For older people with disabilities, the effects on their family of caring for them was another source of worry, exacerbating their feelings of worthlessness. Some were very conscious that the caring role had been reversed. Several said they felt sad that they could not provide for their family, or that family members were limited by having to care for them:

“The most painful thing is to see that my children can’t go anywhere because they’re afraid of leaving me alone.” Female, 62

Many older people with disabilities had become separated from their families, because other family members had stayed in Burundi, been placed in a different camp or migrated to another country. Living apart from their families had an adverse effect on their psychological wellbeing. The dispersal of families appeared to put more pressure on the few family members who were in the camp with their older relative. There might only be one or two of them to take sole responsibility for caregiving and other essential activities. Some women, in particular, said it was difficult when the man they were caring for could not earn an income any more, as they could not make up for the loss of income:

*“It limits our opportunities. If he could, he would go out and see to the family’s needs. But he can’t do that now because he’s not in good health.”
Female family member with a chronic health condition caring for her husband*

It was evident that roles and hierarchies in many families had been disrupted by the conflict, as families had become separated and the condition of older family members had deteriorated, so that those who had previously cared for their families now needed care themselves. This places additional pressures on families as well as contributing to a loss of self-worth and sense of control among older people with disabilities.

Risks to mental health

Trauma, displacement and difficult living conditions place an enormous strain on all the refugees living in the camps. However, older people with disabilities can be particularly affected because of factors related to age and disability. Barriers that prevent them from taking part in social and economic activities or accessing services, combined with poor health, pain, worry about their health and separation from family add to their stress. Lack of independence and no longer being able to take an active role in the household commonly contributed further to feelings of hopelessness and vulnerability:

“I feel very bad, now that I realise I won’t be able to take care of myself. It’s as if I’m dead.” Male, 62, who was shot during fighting in Burundi

Many interviewees talked of low mood, sadness, loneliness, worry and lack of sleep:

*“Sometimes I don’t sleep well. I’m losing hope because I have no one to take care of me.”
Female, 70*

Coping mechanisms were also evident. Some interviewees seemed to accept their situation.

Others indicated how important family support and social activities were for their wellbeing:

*“It’s reached the point where I think about my disabilities and diseases. I try to be rational. I try to reduce the stress by sharing prayers and singing with my fellow Burundian people.”
Female, 60*

3.5 Findings from interviews in Eastern Ukraine

The situation in Eastern Ukraine

The armed conflict that started in Eastern Ukraine in April 2014 has resulted in extensive suffering and significant displacement. It is estimated that between April 2014 and March 2017, more than 9,940 people were killed and 23,455 were injured as a result of the conflict.⁴⁷

The humanitarian crisis in Eastern Ukraine differs from others in the high number of older people, mostly women, affected by the conflict and in need of assistance.⁴⁸ The generally weaker post-Soviet economy, a decrease in the supply of food, goods and services due to the conflict, and the lower value of the Ukrainian currency, have led to states of extreme poverty in the region. The conflict has also further weakened an already weak social support structure.

HelpAge International has been delivering humanitarian assistance to older people in Eastern Ukraine and promoting the inclusion of older people in the humanitarian response since 2015. HelpAge has created a number of community “safe spaces” – centres where older people can take part in social and cultural activities. The centres also refer older people to other community services. HelpAge trains community workers to provide home care for older people. Other activities include setting up peer support groups for older people to visit each other and provide companionship, training partner organisations on working with older people, and working with local government to develop programmes and policies inclusive of older people.



Phillip Sheppard/LSHTM

Key findings

Interviews with older people with disabilities, family members and key informants in Eastern Ukraine showed that older people with disabilities had had particular difficulties escaping the conflict. Money was a problem for all of them, due to low pension levels, restrictive administrative systems, discriminatory attitudes and physical barriers to accessing their payments.

Healthcare was another major concern. Problems included cost, particularly of medication, inaccessible health services and mixed attitudes of health workers.

Living conditions were generally poor and housing unsuitable. Older people with disabilities said their families and neighbours were an important source of support. However, many were isolated and lonely. They valued home visits and humanitarian assistance.

Key informants commented on the challenges of consulting older people with disabilities, lack of long-term funding, and lack of specific guidance. They recognised the importance of collaboration between organisations focused on older people and organisations focused on people with disabilities, and of age and disability training.

More risk escaping from danger

It was evident that the conflict had created particular problems for older people with disabilities. They had found it harder to leave the conflict zones than younger adults or older people without disabilities. Some had delayed moving, or had stayed behind, because of functional limitations, poor health, reluctance to leave their own communities in the absence of anywhere else to live, or because they could not afford to leave:

“Older people have nowhere to go. As soon as the war started, young people left for Kiev or Moscow. Older people don’t have the money to go anywhere.” Male, 87

Interviewees said that since the conflict had begun, prices had risen, services had closed and it was harder to claim their pensions. Consequently, older people with disabilities who could not flee the fighting were not only at risk of bombing and shelling, but also faced extreme difficulty meeting their basic needs. They found it distressing to describe their experience of living through the conflict:

“I used to lie down. That’s all I could do. There were no medicines, no doctors, no pension, no food. I remember that time with horror. How did we survive? I don’t know.” Female, 72

“There was no electricity, gas or running water. We lived through the winter without any heating. We walked along the streets to see if anyone with a furnace could give us hot water for tea. It’s better not to recall it.” Female, 73, crying

The difficult living conditions contributed to worsening health. One couple who had been unable to flee, were troubled by heavy bombing and shelling close to their home. The only place they could hide was in their basement. They lived there for more than a month before being evacuated. During that time, their physical health suffered:

“My wife stayed in the basement all the time. I used to go outside sometimes, but she couldn’t go out, because of the stairs. It affected her a lot. She used to walk without any problem before.” Male, 87

Several interviewees said that older people with disabilities who could not leave the conflict zones had died as a result:

“They stayed behind and died. No one was there to help them.” Male, 76

Although some interviewees said they were suffering from poor mental health, ongoing trauma and sleeping problems as result of their exposure to the fighting, few said they had received any formal emotional support:

“After we arrived here, my wife felt scared whenever she heard loud noises. Last year, when there was a storm, she thought somebody had been shot. It was very difficult to calm her down.” Male, 72

“At night I watch the time go by. I can stay awake until 3.00am. I mistake the sound of thunder for bombing. I’m very nervous.” Male, 80

Concerns about low pension levels

All the older people with disabilities interviewed were worried by not having enough money. Older people with disabilities are particularly affected by poverty as they often have to pay more for healthcare, medicines and transport.

Older people in Ukraine rely heavily on state pensions as their main source of income. As well as an old-age pension, there is a disability pension. This uses a severity classification system to determine the amount of money and type of assistance to be provided, ranging from class 1 (most severe disability) to class 3 (least severe). Pensions, medical care, home visits and housing subsidies (for example, for utilities) are available to people who are registered and have a disability classification. A resettlement subsidy is also available for registered internally displaced people.

Interviewees had a number of concerns about these social protection schemes. All interviewees said that the pensions and subsidies they received were not enough to meet even the basic costs of living, particularly considering their healthcare needs:

“Prices keep rising. The pension doesn’t manage to catch up.” Female, 71

“I thought we would be warm when we were old, but gas costs so much now, our pensions are not enough to pay for it.” Female, 73

Some interviewees said they felt they should be placed in a higher category, considering how their functional limitations were affecting their own and other people’s daily lives.

Restrictive systems for claiming social protection

It was evident that older people with disabilities faced various regulatory and institutional barriers to accessing social protection schemes. The disability pension can be denied to a person who has a family member whom the government deems should be able to care for them. This can make people more dependent on their families as well putting them under financial pressure:

“The government official came to my room. She told her [my ex-wife]: ‘If he was alone we could register him. But he has a daughter. She can take care of him.’ I told her that my daughter has four children and she’s a resettler herself. The official said: ‘That doesn’t concern us. She should take you in. If she doesn’t, she can pay for the care home.’ The care home is expensive.” Male, 65

Some of the interviewees were living in informal or temporary accommodation. Because of this, some missed out on state support. For example, one older man with a disability could not claim his pension because he did not know how to contact the owner of the house he was living in:

“I went to the Social Services Department but they told me the owner of the house I’m living in had to sign the papers.” Male, 87

Bureaucracy was sometimes baffling to those interviewed. The same interviewee had been denied a resettlement pension, but did not know why:

“If we had received our resettlement money, it would have been easier for us. I don’t know why they’re procrastinating. They told me that our village was not on the map.” Male, 87

Stigma and discrimination

According to one key informant, some older people with disabilities do not register for the disability pension because of the stigma attached to having a disability, as well as confusion about how the system works. For those who do register, a lack of consideration by staff administering the scheme can leave them feeling frustrated and humiliated:

“Every three months, they have to take me down from the fourth floor and bring me back up again. I’ve told them that it would be better if a postman could bring my pension to the flat. They say that’s not permitted for resettlers. They make fun of the resettlers and disabled people.” Male, 65

A few interviewees said they felt vulnerable to theft when they collected their pensions in public places.

Physical barriers to claiming social protection

As with the disability pension, the distribution of the state pension does not take into account the physical barriers faced by older people with disabilities. Interviewees described long journeys to banks, lack of affordable transport and inaccessible buildings. This was particularly the case for displaced people who were required to go to the bank in person to verify their eligibility. The financial and physical strain that this requirement places on them is evident from the experience of one interviewee who had had a leg amputated:

Man: “They invented laws saying that resettlers can receive a pension if we have a card. Every year they issue a new card. I have to go downstairs from the fourth floor.”

Woman: “I pay for people to take him down. It’s not so easy.”

Man: “Two comrades came. I felt awkward. They were groaning because I’m heavy.”

Woman: “Then he slipped. So he jumped down on one leg. At the bank, he had to go to the third floor. It put an overload on the leg. He was hospitalised and his second leg was amputated.”

One of the key informants interviewed also said that many older displaced people, particularly those with disabilities, faced physical barriers to obtaining their displaced person’s certification. For example, they may not be well enough or social service departments may be too far for them to reach to collect their certificate. Without the certificate, they cannot receive a pension.

Problems paying for healthcare

Healthcare emerged as a major issue. Older people with disabilities typically have greater healthcare needs than the general population, but face a range of barriers to receiving services. One of the most common problems described by older people with disabilities was paying for healthcare, particularly medication. Several interviewees who were registered as having a disability said that doctors and nurses would visit them at home if they were called, which they found very valuable. However, some could not then afford the recommended treatment:

“If I call a doctor, they come. If necessary, I call an ambulance. They prescribe medicines, but our finances are limited.” Family member

Several interviewees said they could not afford the healthcare services they needed, whether general or specialist:

“The doctor said: ‘If you have 20,000 hryvnias [US\$759], we’ll do the surgery on your leg.’ I said: ‘Where will I get 20,000 hryvnias from? I don’t have any such money.’” Female, 83

“I would like to solve my hearing problem but I don’t know how I can. Hearing aids cost so much.” Male, 81

The interviews showed that many older people with disabilities were reliant on medication. Many had to make difficult choices between spending their limited money on food or medicine. Often, medication appeared to take precedence. A woman living with an 83-year-old woman with severe mobility limitations and a son with epilepsy said:

“We sometimes go without food. We spend most of our money on medical items. We haven’t enough money. That’s why we sometimes have nothing to eat.” Female, 68

Health services out of reach

Physical barriers were also evident. Health services, already suffering from post-Soviet under-investment, have deteriorated further because of the conflict. Many health workers, including doctors and specialists, have moved away. Many health facilities along the contact line (the 500-kilometre line of separation between Russian-supported separatist districts of Donetsk and Luhansk and the rest of Ukraine) have been damaged, and those that are in non-government controlled areas are no longer accessible. The limited availability of services clearly had an impact on the interviewees. For example, one man with vision and mobility difficulties said he could not travel the long distance to the city where ophthalmic services were provided.

Older people with disabilities found long waiting times at health facilities particularly difficult. Several said they had to be at the hospital by 6.00am to queue to see a health professional. Some had difficulties finding accessible transportation, especially early in the morning. This meant they arrived later and queued for longer, with the risk that they would not be seen at all:

“There are crowds of people queuing for tickets to get an appointment. You have to queue from 6.00am to get a ticket. If you come later, there are no tickets left.” Male, 81

In theory, public transport is free or reduced for pensioners. However, according to one key informant, this is often not the reality in towns and villages affected by the conflict.

Hospitals are often inaccessible to older people with disabilities. Many hospitals have no toilets, lifts, or places to lie down in waiting areas. Some interviewees said they were put off going to hospitals because of the poor conditions:

“There are no lifts in the hospital. No lifts! It’s hard for me to climb upstairs.” Female, 68

“The doctor told us to arrange for my mother to have an examination – to take a taxi to the hospital. But how would we get her to the second floor? We refused to go.” Family member

An additional complication for some displaced older people with disabilities was that they could only receive health services in the area in which they were registered. It could take a long time to change the area of registration. For one older woman with diabetes, it took the government two years to change her area of registration. During this time, she had to regularly cross the contact line into the non-government controlled area to receive insulin, exposing her to the danger of shelling, landmines and bombs.

Mixed attitudes of healthcare staff

Attitudes of staff could also present barriers. Older people with disabilities had varied experiences of interacting with healthcare staff. Some spoke positively about doctors making home visits when they were called. However, this was not the experience for everyone:

“I asked an employee from the Social Services Department to go to the clinic to ask the doctor to come. When she returned, she told me that the doctor had got angry and asked why she should come to my place. Doctors don’t want to do that. If you give them money, they agree to come.” Male, 80



Phillip Sheppard/LSHTM

Unsuitable housing and poor living conditions

Living conditions in Donetsk and Luhansk are generally poor. Flats are often crowded and inaccessible to people with disabilities. Many of the interviewees were living in large, Soviet-style, poorly built and maintained high-rise apartment blocks. These either had no lifts, or had lifts that were poorly maintained or barely large enough for a wheelchair.

The poor housing conditions limited older people's independence and opportunities for social interaction. One interviewee explained that, because of the poor conditions they were living in, they felt uncomfortable about hosting their church group. Some older people with disabilities appeared to be prevented from leaving their homes:

“There are steps. I don't take him out because we don't have ramps. I could drop him.”
Family member

“The only thing that upsets us is that she can't go out. Can you help us install wheelchair ramps so we can transport her from here?” Female, 68

Extreme poverty and high utility costs make winter particularly challenging. Although some interviewees said they received a utility subsidy, many said they could not afford to heat their homes. This was particularly distressing for those who were largely housebound and in poor health.

Most people interviewed were living in the community. Some were living in collective centres for people with disabilities. However, they were not necessarily protected against forced eviction:

“We were brought to a collective centre. We lived there for a while. Nobody wanted to pay the owner, even when people started receiving resettlement money. The owner made everybody leave. He's a private businessman. It was terrible. He switched everything off, including the water and lifts, to evict us. We were living on the 12th floor.” Male, 65

Importance of family and neighbours

The interviews highlighted the importance of family, friends and community to older people with disabilities. Some interviewees said they received little or no family support. For others, their families were their main source of support with finance, self-care and access to health services. Their families had also helped them escape from the conflict. Community support was also important for enabling older people with disabilities to live in the community:

“Everybody tries to help. They do their best. They see me walking and help me carry my bag.”
Female, 71

Neighbours were often cited as buying food and other supplies for older people with disabilities, especially those without family nearby. Neighbours also helped with self-care and household chores. Sometimes older people with disabilities borrowed money from friends. One woman with mobility and hearing difficulties, living alone, said:

“My neighbours are very good. My neighbour buys bread for me. Yesterday, she bought some sugar for me too.” Female, 90

Family members were generally supportive of their older relatives and committed to caring for them. However, there were some challenges associated with caregiving. Already poor families were further impoverished by high healthcare costs and inability to work because of their caregiving responsibilities. A relative of a 78-year-old man with an intellectual disability said:

“I can’t go to work because of him.” Family member

Several family caregivers, particularly older people who had health problems themselves, said that caring sometimes made them feel stressed and worried:

“How can my father get washed? He climbs into the bath but sometimes he doesn’t have enough strength to get out. It’s a problem. I always feel stressed.” Family member

“I leave him at home. He has a mobile phone. I talk to him on the phone. I ask him how he’s feeling. I try to do the shopping as quickly as I can. The members of our church help me buy some things. I try to fit my schedule in with theirs so that they buy things for me and deliver them to our house by car.” Family member

The interviews also suggested that caring could limit their social life. Some said they did not have enough time to socialise in addition to caring. One woman whose husband had mobility problems and heart disease said:

“We don’t invite our friends round. My husband doesn’t like people to come. Because of his disease, it’s very difficult for him to see other people.” Family member

Social isolation and loneliness

Despite support from their families and communities, older people with disabilities often felt isolated, lonely and anxious. Some said they went for walks, talked to neighbours or attended church services. However, many, particularly those with more severe functional limitations or intellectual impairments, seemed to spend most of their time at home and had little contact with other people:

“I don’t go out the house. I just look out of the window.” Female, 78

Factors related to the conflict, as well as physical and financial barriers, contribute to the social isolation of older people with disabilities. Social structures and community networks in these areas have been substantially weakened with the deterioration of the economy. Many services and facilities have shut down, limiting opportunities for social and leisure activities:

“We used to be able to go to places. We could go to the cinema or the club, or we could go into the forest for some fresh air. It’s got worse and worse. We can’t go there any more because there are mines and artillery shells.” Female, 68

Many older people who have been displaced have become separated from their families and friends, and their support networks have declined. Lack of accessible transport makes it harder for them to visit people:

“How can I visit my friends [in the non-government controlled area]? There’s no one to drive me. I can’t go by bus and I don’t have enough money to hire a taxi.” Female, 73

Some older people with disabilities said they did not feel well enough to socialise. For some, poverty, inaccessible buildings, and inaccessible and unaffordable transport prevented them from seeing their friends:

“I have a friend, Liusia, but she won’t come. She can’t walk without crutches. I’d have to order a taxi for her, but it would cost 60 hryvnias [US\$2.30] there and back.” Female, 86

Some interviewees said their friends and neighbours had died, leaving them on their own:

“I doubt if anyone will be able to help me. My friends died a long time ago. I’m alone. The neighbours in our block of flats have started to die. Five of my neighbours died in January and February.” Male, 80

Apart from one woman who was very active in a disabled persons' organisation, and two more who attended church, most older people with disabilities did not appear to be taking part in meetings, social gatherings or other events away from the house. Some said that if they went out, they felt excluded. One man with limited mobility and a hearing impairment said:

“The main problem is that when people lower their voices at a meeting, I can't hear them. I'm not involved.” Male, 81

The interviews suggested that some older people, particularly those with physical disabilities, were leading unnecessarily restricted lives. This may reflect a tendency by carers and family members to be over-protective and unaware of the importance of movement and social participation. The key informants we interviewed also recognised this issue. They are working with HelpAge International to support home-based carers and family members to show older people with disabilities how to use assistive devices and encourage them to be more mobile.

Some older people who had lost their independence said they felt “inconvenient” or a burden on their family and community, “too old to be of use”.

“A few days ago, I was sitting on a bench near the sixth house. Someone asked me why I was sitting there. I said: ‘I'm resting! I need a breath of fresh air,’ She offered to help me. But I felt it would be inconvenient for her.” Female, 71

Not all the older people with disabilities understood what caused their disability. One thought it was the result of sin:

“I don't know the cause of my disability. I think it's because I've been sinful.” Female, 72

Value of home visits and humanitarian assistance

Older people with disabilities said that home visits by HelpAge community workers and (in a few cases) social workers were their main external source of support. The community workers or social workers helped them carry out daily activities such as shopping and household chores. Those who received this regular support said they found it very valuable.

Daughter: “The girl comes once a week. If I'm at work or delayed, I know she will come.”

Mother: “Such a clever girl comes!”

Daughter: “They also gave us incontinence pads and then gave us firewood. I don't know how we would have survived the winter otherwise.”

Interviewees said they had received assistance from various local, national and international organisations, particularly early on in the conflict. These included Caritas, Red Cross, Rinat Akhmetov Humanitarian Centre, and local disabled persons' organisations. They credited these organisations with providing supplies such as food, hygiene kits and medicines, mobility aids and money to repair their homes. Being given food or food vouchers also meant they could use their pensions for other necessities such as medicine. Some had also received help with documentation and government processes, and been given information about other sources of support.

Humanitarian organisations clearly provide important services that help to meet the basic needs of older people with disabilities. However, with the exception of one woman who was an active member of a disabled persons' organisation, there was no evidence that older people with disabilities were being consulted by any of these organisations or involved in their activities. Further, some interviewees said that services they had previously received had stopped after a short period:

“Unfortunately the project has closed. It's bad. I wish they would start more projects like this one. They gave us things. They gave us a chair that made it easier for her to get washed and go to the toilet.” Female, 68

“During the first year and a half, they helped us. But for more than a year there's been no help – no food or anything else.” Family member

Key informants' perspectives

Key informants identified several factors that made it either harder or easier for local and international organisations to meet the needs of older people with disabilities.

Challenges of consultation

Several local key informants agreed it was important for older people with disabilities to be included in developing, implementing and evaluating programmes. However, consultation is felt to be particularly challenging in this complex context where affected people are spread across a wide geographical area (along a 500-kilometre line of contact), many living in small, remote communities which are hard to reach because of fighting and shelling.

Some said consultation rarely happened in practice:

“The policies and programmes were developed by practitioners and key informants. Older people were not included.” Key informant

Lack of long-term funding

Key informants said that all the organisations working in Eastern Ukraine were limited by lack of long-term funding. One key informant said that this was as a result of the protracted nature of the conflict, and a misconception from the international community that the conflict had subsided – despite recent reports of continued high numbers of people crossing contact lines and ongoing conflict-related civilian deaths and injuries.⁴⁹ The lack of funding has resulted in uncertainty and high turnover of staff in many organisations, affecting their ability to deliver of programmes and services.

Inapplicable guidelines

One key informant said the guidelines, standards and policies they were provided with were lengthy and very general to humanitarian crises. They were not very applicable to Ukraine or the conflict in the eastern part of the country:

“Some of the actions are really not applicable to the Ukrainian context. They’re not contextualised.”
Key informant

They recommended involving local key informants and older people with disabilities to develop programmes that would be tailored to the target population group. They also called for shorter, more accessible documents, containing more practical guidance and concrete examples of how to implement particular guidelines and policies.

Importance of collaboration

Key informants highlighted the importance of collaboration between different organisations to provide inclusive humanitarian assistance. Representatives of local NGOs said they worked with the city council and local government as well as healthcare professionals and social workers to identify older people with disabilities. Small, local organisations often collaborated with national or international organisations to deliver services.

Value of training

Key informants also identified training as important. They spoke highly of the age and disability training conducted by HelpAge International. They said this had helped them change their attitudes towards older people with disabilities and the way they worked with them. For example, a representative of a local organisation that provides assistive devices said that after the training, they started recording more data on age and disability. They collaborated better with government and large international organisations and felt more comfortable working with older people with disabilities.



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4. Discussion and conclusions

According to available data, up to 14 million older people with disabilities may be affected by humanitarian crises. The number is expected to rise as the global population continues to age and more people are affected by humanitarian crises.

Drawing on available literature, analysis of survey data and interviews with older people with disabilities and humanitarian actors, this research highlights the different experiences of older people with disabilities, the rights they are denied, and the risks they face. Some efforts are being made to address the needs of older people with disabilities in humanitarian crises (see box on page 41: Practical ways to include older people with disabilities). However, our research identifies a range of barriers that prevent older people with disabilities from exercising their right to humanitarian assistance, protection and participation, and the factors that enable them to do so.

Shortage of data

We were only able to identify two datasets from humanitarian settings that contained data on older people with disabilities. Neither of these contained data specific to the crises (for example, on access to humanitarian assistance). This highlights a significant need for further research into the experiences of older people with disabilities in humanitarian crises.

Disability common in older age

The analysis of existing disability survey databases showed that disability was common among older people.

The prevalence of disability in people aged 60 and over ranged from 22 per cent in Guatemala to 39 per cent in India. The prevalence was much higher among people aged 80 and over, ranging from 36 per cent in Palestine to 65 per cent in India. This reflects the risks of disease, injury and chronic illness that accumulate over the lifespan.

In each study, disability was measured by asking older people about the level of difficulty they had performing certain functions. The prevalence varied between the three settings. Disability is heavily influenced by personal and environmental factors. For example, refractive errors can impair a person's vision, but how much this affects their ability to see may depend on whether they are wearing spectacles.

Access to health and rehabilitation services, support from family and other sources, cultural differences in how people perceive themselves to be functioning, and different ways of interpreting questions may all influence the prevalence of disability measured through self-reported functioning.

Link between disability and poverty

Poverty and disability are considered to be intrinsically linked. A recent systematic review in low- and middle-income countries found strong evidence to support the link between disability and economic poverty.

The quantitative data analysis showed that across different low- and middle-income countries, older people with disabilities were less likely to work, had more limited opportunities to participate in society and had greater healthcare needs than older people without disabilities. In Nepal, older people with disabilities were more likely to be at high risk of healthcare spending-induced poverty.⁵⁰

These findings concur with studies in Kenya, Bangladesh and the Philippines where older people with visual impairment were found to be poorer and less likely to work than older people without visual impairment.⁵¹ Given that older people are at greater risk of poverty,⁵² these findings suggest that older people with disabilities are even more likely to be among the poorest of the poor.

Although the analysis indicated that older people with disabilities were at greater risk of poverty, it did not find a significant difference between the economic status of older people with and without disabilities. The findings highlight the complexities of assessing poverty among older people. Ownership of household assets and building materials of the house were used to measure people's socioeconomic status. This system typically provides a longer-term measure of economic poverty⁵³ than, for example, measuring income or expenditure. It may, therefore, not reflect recent changes in a person's circumstances, for example, if they have become disabled later in life. Further, it is a measure of household economic status and does not tell us about the distribution of resources and opportunities for individuals within the household. Finally, it does not take into account other factors that affect a person's economic status, such as work, education and health. As our findings suggest, these indicators may be more relevant to measuring disability in older age.



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Barriers to gaining an income

Poverty was a common theme identified in the qualitative research. Poverty underlay many of the difficulties experienced by older people with disabilities in Eastern Ukraine and refugee camps in Tanzania. While poverty is a common problem in these settings, older people with disabilities are likely to be particularly affected, as they are likely to have to pay more for healthcare, medication and transport, but are less likely to be working. Further, in Ukraine, there was evidence of barriers preventing older people with disabilities from receiving their social protection entitlements.

In Ukraine, people rely heavily on social pensions as their main source of income in older age, even though the amount they receive does not meet their basic needs. However, the research provided evidence that a number of physical, institutional and attitudinal barriers were preventing older people with disabilities from receiving state benefits. Physical barriers included long journeys to banks, lack of affordable transport, and inaccessible homes and public buildings such as banks. Institutional barriers included the requirement for displaced people to present themselves at the bank to verify their eligibility, and being denied a disability pension

if they had a living relative, even if the relative had moved to a new area because of the conflict and no longer lived with them.

Lack of consideration by staff suggested a need to train government employees on age and disability issues, to encourage them to change their attitude and to advocate for older people with disabilities to be included in the social welfare system.

In camps in Tanzania, the interviews showed that it was harder for older people with disabilities to find work than for other people in the camps. Interviewees described the negative social, financial and emotional impact of losing the opportunity to work because of their disability, poor health and displacement. In the absence of social protection schemes, many expressed a desire to earn an income, for example, by setting up a small business at home or nearby. However, key informants suggested that older people with disabilities were not being included in livelihood programmes, which focused on younger adults.

These findings highlight the importance of working with and listening to older people with disabilities in order to identify their capacity to participate in work, and design livelihood programmes that are age- and disability-inclusive.

Reduced access to healthcare and humanitarian assistance

Older people with disabilities have the right to safe and dignified access to humanitarian assistance on an equal basis with others. The research showed that family and friends, accessible and affordable transport, and proximity to services and distribution sites made it easier for older people with disabilities to exercise this right. However, the research also suggested that older people with disabilities might be disproportionately affected by environmental and institutional barriers that increased their risk of exclusion.

People tend to have more healthcare needs in older age.⁵⁴ Our quantitative analysis showed that healthcare needs became higher still among older people with disabilities. In Ukraine, the costs of medication and other health services were a major concern for older people with disabilities, impoverishing them further. Many were forced to choose between spending their money on food or medication. Some could not afford the health and rehabilitation interventions they needed. In Nepal, higher healthcare expenditure by older people with disabilities increased their risk of poverty.

In Ukraine, home visits by doctors were an important way for older people with disabilities to obtain healthcare. However, some older people with disabilities found that environmental barriers (such as lack of accessible transport, lack of lifts, long queues, and nowhere to lie down in waiting areas) limited their access to hospitals and specialist services. Similarly, a study from New Zealand found that destruction of infrastructure prevented older people with visual impairments from reaching health services, leading to worsening health.⁵⁵

In refugee camps in Tanzania, healthcare is provided free of charge. Most interviewees said they could reach the hospital in their camp (often with support from their family). However, lack of medication to treat their condition was a prominent issue. This is likely to be a particular problem for this group, considering they are likely to have higher healthcare needs.

In both Ukraine and Tanzania, the qualitative findings suggest that access to rehabilitation varies. Interviewees in both settings said they found the mobility devices and rehabilitation they had received useful. However, some had had difficulty obtaining other assistive devices (such as hearing aids) and specialist services (such as eyecare). This suggests that these services need to be made more easily available to older people with disabilities to enable them to be independent.

Some of the studies we reviewed highlighted difficulties that displaced people had in accessing food and other distributions, although they did not provide details of what the barriers were.^{56, 57, 58, 59}

In Tanzania, many interviewees were able to access humanitarian assistance, particularly with support from their families. Incentive workers also provided information about services and facilitated their access to healthcare. Key informants said that humanitarian agencies were making encouraging efforts to make food distributions accessible. For example, they provided transport for older people and people with disabilities and gave them priority at food distributions. However, some interviewees said they could not reach the distribution sites. Others said they could not navigate the crowds or carry their rations home.

Institutional barriers to accessing distributions also emerged. For example, refugees were required to go in person to distribution points, making it difficult for family members to collect distributions on their behalf of their relatives if they could not get there themselves. This suggests a need to review policies and processes to be fully inclusive of older people with disabilities.

Another problem was too little food and not enough variety. The same problem was noted as a cross-cutting issue affecting different vulnerable groups in previous assessments in the two camps.⁶⁰ Key informants suggested reducing the interval between food distributions to older people with disabilities.

In Ukraine, the main sources of assistance to older people with disabilities were home visits by HelpAge community and peer-to-peer workers, and state social workers. Interviewees said these were important to enable them to live independently and to provide company. Different organisations had provided food and non-food aid earlier in the conflict. However, many of the projects had ended, with international humanitarian agencies reducing their funding.

The qualitative research suggested that older people with disabilities might be disproportionately affected by poor housing conditions, which are common in humanitarian settings. For example, living in apartment blocks without lifts makes older people with disabilities more likely to become housebound and socially isolated. Sleeping on rough floors, as was the experience of some older people with disabilities in Tanzania, exacerbates existing health conditions.

Greater protection risks

Older people with disabilities have the right to protection without discrimination in humanitarian response. However, this research highlights the protection risks they experience.

Older people with disabilities in both study populations had difficulty escaping from the conflict because of physical and financial barriers. This finding supports limited previous research which suggested that older people with disabilities were at greater risk of being abandoned during evacuations from conflict in Syria and Ethiopia,^{61, 62} and found evacuation routes inaccessible to them after an earthquake and tsunami in Japan.⁶³ Our research also showed that prolonged exposure to conflict worsened the physical health of older people with disabilities and caused trauma and anxiety.

Protection risks following displacement included having household items stolen in Tanzania and feeling vulnerable when collecting pensions in Ukraine. Further, although many older people with disabilities appeared to feel they were being treated well by their communities, some said they had faced discrimination based on their age and disability. For example, some had had difficulty claiming their pensions in Ukraine, and some had been told by younger people to leave the camp in Tanzania.

Threats to independence, dignity and participation

Older people with disabilities have the same right as everyone else to live in dignity. However, threats to exercising this right emerged in these complex, conflict-affected settings. For example, older people with disabilities suffered from lack of privacy and accessible toilets in camps in Tanzania and felt humiliated by inaccessible welfare state systems in Ukraine.

Barriers that prevented older people with disabilities from being independent and having control over their lives were also evident. These, in turn, seemed to damage their self-esteem and psychological wellbeing. The quantitative analysis showed that older people with disabilities were more restricted from participating in social, community and civic life than older people without disabilities. Their limited independence and social isolation also emerged in the qualitative research.

The value of social participation and relationships to wellbeing in older age is well established.⁶⁴ In Ukraine, older people with disabilities seemed to particularly value social interaction during visits by community workers. Visits from friends were valued

in both settings. The few older people with disabilities who took part in social activities benefited from these in terms of their wellbeing. However, the majority of interviewees rarely, if ever, attended social events or meetings outside their homes.

Lack of independence and social isolation appeared to result from multiple interacting factors related to displacement (such as separation from family and closure of facilities in Ukraine), poverty, fatigue and ill-health, and physical barriers (such as inaccessible housing and public buildings, inaccessible transport and lack of assistive devices). Activities aimed at improving the opportunities for older people to socialise exist in both settings (such as community “safe spaces” in Ukraine, and “multi-purpose safe and inclusion spaces” in Tanzania). However, our findings suggest that these warrant attention to make them more disability inclusive. Further, our findings point to an urgent need to install low-cost adaptations to people’s homes (such as wheelchair ramps and ropes to guide people to toilets), as well as assistive devices and rehabilitation services.^{65, 66}

The qualitative research also suggested that some older people with disabilities might be leading more restricted lives than necessary. This may reflect a misconception by older people with disabilities and their families that disability is an inevitable part of ageing. They may not realise that assistive devices, rehabilitation and accessible environments and systems can promote more active ageing. Key informants suggested that family members and carers might be overprotective.

This echoes findings in previous research.⁶⁷ It suggests a need to promote awareness of the value of activity, rehabilitation and enabling environments. Older people with disabilities and their carers need to be sensitised about the rights of older people with disabilities and know how to claim these. With a few exceptions, the interviews suggested that older people with disabilities in both settings were more likely to be passive recipients of humanitarian assistance than to be actively involved in decision-making processes on issues that affected them.

The experience of older people with disabilities aligns with findings from the stakeholder interviews. Key informants said that, despite recognising that it was important to include older people with disabilities, they were not consulting or including them to plan or implement their programmes. There is a need to focus more not just on addressing the needs of older people with disabilities and enabling them to access their rights, but also on identifying, through consultation, the capacities of older people with disabilities and ensure they are engaged in decision-making processes.⁶⁸



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Damage to psychological wellbeing

Findings from the literature review and quantitative and qualitative research suggest that older people with disabilities might be particularly at risk of poor psychological wellbeing in crises settings. They are more likely to face barriers to social participation, have poor health and be living in pain. Prolonged direct exposure to conflict, loss of their previous role in the family, loss of independence and protection risks are also contributory factors.

This finding echoes findings from previous research in which people with disabilities (all ages) identified psychological impact as the second most important impact of humanitarian crises on them.⁶⁹

Importance of family and neighbours

The research showed that family and neighbours played a key enabling role in the lives of older people with disabilities in both settings. They assisted with daily activities, facilitated their access to protection (such as evacuation) and assistance (such as health services and distribution points), and provided companionship. This supports previous research among people with disabilities (of all ages) in humanitarian crises, which found the family to be the main source of assistance.⁷⁰

Our research highlights a need for the role of family members and carers to be better recognised in humanitarian contexts. This is important because

older people with disabilities often become more dependent on their families in humanitarian crises, where barriers limiting their independence are often created or exacerbated.

Intersection of age and disability

Many of the issues raised in our research are common to those identified in previous research on older people or people with disabilities.^{71, 72, 73, 74} However, in humanitarian crises, difficulties experienced by older people may be exacerbated by having a disability, and vice versa. For example, our data shows that older people with disabilities have higher healthcare needs than older people without disabilities. They are therefore likely to be disproportionately affected by the barriers that limit their access to health services.

Physical and institutional barriers to accessing aid distributions are also likely to be exacerbated. Older people are more at risk of poverty than younger adults.⁷⁵ Older people with disabilities face additional barriers to maintaining their income, such as finding it harder to work or access social protection, making them even more likely to be among the poorest of the poor.

Key to understanding the intersectionality of sex, age and disability is collecting the right data, including data disaggregated by sex, age and disability. If this is not done systematically, the complexities of communities affected by humanitarian crises will not be properly understood.

Disconnect between age-focused and disability-focused organisations in the humanitarian sector

In general, humanitarian policies and guidelines appear to lack attention to the intersection of age and disability. The creation of the Age and Disability Consortium⁷⁶ to develop a set of inclusion standards is one effort to address this disconnect. However, there is a risk that older people with disabilities may be missed in efforts towards both age and disability inclusion.

Representatives of international organisations commented on a disconnect between organisations and programmes focusing on older people and those focusing on people with disabilities. Older people were not being included in the work of disability-focused organisations and people with disabilities were not being included in the work of organisations focusing on older people. They were concerned that responsibility for addressing the needs and rights of older people with disabilities should rest not only with age-focused or disability-focused organisations, but also with all humanitarian organisations.

Considering that disability is most common among older people, and that numbers of older people are increasing with global population ageing, there is a need to increase the visibility and meaningful inclusion of older people with disabilities in humanitarian action. This involves not just addressing their needs in terms of access to assistance and protection but also ensuring that their rights are upheld and they can have full and meaningful participation in decision-making on issues that affect them and their communities.

Findings from the interviews in this study suggest that, while programmes in Eastern Ukraine and refugee camps in Tanzania are to some extent addressing needs, older people with disabilities are not being fully included in decision-making processes in either setting. Interviews with local key informants suggested that, despite wide recognition of the importance of participation, in reality this is often lacking. There is a need, therefore, for greater sensitisation and efforts by humanitarian actors to ensure that older people with disabilities are being included in the development and implementation of programmes and humanitarian action.

Collecting, analysing and reporting data on age and disability is important for making older people with disabilities more visible in humanitarian contexts. They need to be identified, and their needs and capacities assessed to inform inclusive programmes.⁷⁷ This point is illustrated in the two study settings, where older people with disabilities were identified and included in humanitarian programmes run by HelpAge International.

Global and local key informants noted that collecting age and disability data led to better programmes. However, they also highlighted challenges to collecting data on people with disabilities, including a lack of consensus on how to measure disability, and concerns about the time it took to collect this data. This view may suggest that the humanitarian system is set up more to suit those delivering assistance than those they are supposed to be working for.

The Humanitarian Inclusion Standards for Older People and People with Disabilities advocate using the Washington Group short set of questions.⁷⁸ While this set of questions has recognised limitations – for example, there is no question about psychological wellbeing – it provides a relatively quick and simple means of collecting disability data, which is being increasingly adopted. A project by Humanity & Inclusion, Disability Statistics in Humanitarian Action, has supported partners to use the Washington Group questions. They have found the answers helped them identify more people with disabilities and inform programming.⁷⁹

The quantitative analysis of existing disability surveys (with nested case control studies) highlights the value of using disability- and age-disaggregated data to identify inequalities. This helps identify priority areas for humanitarian policy and programming and provides evidence for advocacy to promote the meaningful inclusion of older people with disabilities in policies and programmes. However, population-based surveys containing data on people with disabilities in humanitarian settings are sorely lacking. There is an urgent need for disability surveys to be carried out in different crises-affected populations to inform policies, programmes and advocacy for inclusive humanitarian action.

Practical ways to include older people with disabilities

Our research suggested a number of practical ways to include older people with disabilities in humanitarian response:

- Collect data on age and disability to make older people with disabilities more visible and inform inclusive programmes.
- Support older people's associations and disabled people's organisations to work together.
- Build on older people's capabilities and the significant roles that they have often played in their communities prior to the humanitarian crisis.
- Provide transport for older people with disabilities to reach services:
 - In refugee camps in Tanzania, HelpAge community workers used three-wheeled vehicles to take older people with disabilities to food distribution points and reach centres. In camps in West Darfur, HelpAge introduced "donkey-cart ambulances" to take older people to health centres.
- Prioritise older people with disabilities at health services and food distribution sites:
 - In camps in Tanzania and in West Darfur, some medical agencies allocated specific times to attend to older people, reducing the time they had to spend queuing.
- Distribute cash to people at home:
 - In Nepal, old-age and disability allowances were distributed to older people with disabilities in their homes following the earthquake.
- Organise home visits and opportunities for social interaction:
 - In Eastern Ukraine, community workers regularly visit older people with disabilities in their homes to assist them with daily living and provide companionship. Peer support groups have been set up in Ukraine through which older people provide "outreach" home visits to those who are housebound.
 - In Tanzania, incentive workers walk through the camps to provide information to older people with disabilities about services and assist them to obtain food and healthcare.
- Set up "safe spaces" for older people and people with disabilities.
 - In Eastern Ukraine and refugee camps in Tanzania, centres have been set up where older people and people with disabilities can socialise and obtain information.



Phillip Sheppard/LSHTM

5. Recommendations

Drawing on our conclusions, we make the following recommendations to humanitarian donors, policy makers and practitioners.

1. Demonstrate leadership and institutional will

- Use the Humanitarian Inclusion Standards for Older People and People with Disabilities to guide organisation-wide inclusion activities and the development of policies, programmes and technical approaches.
- Ensure that NGO senior staff are accountable for their responsibility for including older people with disabilities in humanitarian work, not viewing this as the responsibility only of the disability or age sector. Make sure they are familiar with the relevant policy and legal frameworks and processes (such as the Core Humanitarian Standards and UNHCR registration process).
- Support humanitarian response work only where data that is fully disaggregated by sex, age and disability is used to plan, manage and monitor activities.
- Strengthen alliances between organisations focused on disability and older age at all levels – local, national and international.
- Allocate funding for organisations to include older people with disabilities in all stages of the project cycle in their humanitarian work.

2. Strengthen evidence and data

- Routinely collect, analyse and use data on sex, age and disability to locate older men and women with disabilities, understand their needs and capabilities and the barriers they face to accessing humanitarian assistance and protection, and develop or advocate for humanitarian policies, programmes and activities that are fully inclusive of older people with disabilities. Continue to collect such data throughout the programme to monitor progress towards inclusion.
- Research the experiences of older people with disabilities in humanitarian contexts, and the extent to which their right to safe, dignified access to assistance and protection is being fulfilled:
 - Carry out all-age disability surveys in humanitarian settings.
 - Explore the experiences of older people with disabilities in humanitarian crises, particularly where HelpAge International is not operating, including looking in more detail at gender differences. Include older people without disabilities as a comparison group.
 - Explore in more depth the specific issues affecting older people with disabilities, such as protection needs, healthcare needs (particularly for non-communicable diseases), access to food, and opportunities for social participation. Include mental health and cognitive impairment in data collection.



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3. Promote participation and empowerment

- Recognise the rights of older people with disabilities in accordance with humanitarian principles, and the specific barriers they face to accessing protection and assistance.
- Recognise and identify, through consultation, the participation and capacities of older people with disabilities in humanitarian response programmes (for example, the social roles they play in their communities).
- Put available tools, training and guidance to use to engage older people with disabilities in decision-making processes and include them in all stages of planning, implementation and monitoring of humanitarian response.
- Support older people with disabilities, their families and carers to know about, advocate for and claim their rights and entitlements, in order to access assistance and protection and to promote active ageing.
- Support humanitarian actors, service providers, older people with disabilities, their families and carers to understand the value of activity, rehabilitation and enabling environments in making it easier for older people with disabilities to participate in society.

4. Change attitudes and approaches

- Encourage humanitarian actors to understand how inclusion of older people with disabilities is key to meeting humanitarian standards and commitments, including through provision of high-quality training and inductions.
- Support humanitarian actors to better understand protection risks for older people with disabilities (such as the risk of being left behind during evacuation, vulnerability to theft and risks arising from becoming separated from their families) to support preparedness and response.
- Invest in activities to tackle age and disability discrimination, such as awareness raising, training for humanitarian actors, campaigning (for example, through Age Demands Action) and supporting older people's associations and disabled people's organisations to join forces to give older people with disabilities a stronger voice.

5. Put inclusion principles into practice

- Support older people's associations and disabled people's organisations to work together as part of humanitarian responses.
- Influence mainstream organisations to promote the systematic inclusion of older men and women with disabilities at all stages of the response to make sure that no one is left behind.
- Adapt guidelines, standards and training on age and disability inclusion to better address the intersection of sex, age and disability.
- Support governments to make social protection systems accessible to older people with disabilities in humanitarian contexts. This requires adjusting pre-crisis systems and criteria. For example:
 - Provide universal or near-universal social pension schemes based on simple eligibility criteria.
 - Develop delivery mechanisms that enable access (such as making buildings and transport accessible, providing age and disability sensitivity training to staff, and establishing a system for a proxy to collect a pension for an older person with disability who is unable to do so).
- Support healthcare providers to make health services accessible to older people with disabilities and to provide the medication, rehabilitation, assistive devices and psychosocial services they need.
- Advocate for low-cost adaptations to housing infrastructure and water, sanitation and hygiene facilities so that older people with disabilities can live more safely and independently.
- Promote home visits by other older people and community workers to older people with disabilities who cannot leave their homes, to provide practical assistance, information and companionship.
- Support community social activities for older people to be inclusive of those with disabilities by identifying and removing any environmental, financial, attitudinal and institutional barriers that may limit their access.
- Promote the independence of older people with disabilities without discrimination on the basis of age and disability. Identify the capacities of those who wish to work and include them in livelihood programmes.
- Recognise the role of family and social structures in supporting older people with disabilities when designing and delivering humanitarian programmes, while also recognising the breakdown of traditional social structures during an emergency.

Appendix 1

Disability surveys included in the secondary data analysis

	Year	Location	Total sample size in full survey (people aged 60+)	Disability assessment method
India	2012	Mahbubnagar District, Telangana State	3,574 (352)	Self-reported functional limitations (Washington Group extended set)
Cameroon	2011	Fundong District, North-West Cameroon	3,567 (429)	
Guatemala	2016	National	13,073 (1,148)	
Nepal	2016	Tanahun	5,692 (915)	Self or proxy-reported functional limitations (WG extended set)
Haiti	2011	Port-au-Prince	3,383 (434)	Self or proxy-reported functional limitations (WG short set)
Palestine	2011	Palestinian Territories	88,046 (4,371)	Self-reported functional limitations (questions similar to WG extended set)

Appendix 2

A note on statistical methods

An odds ratio (OR) measures how strongly the presence of one characteristic (such as disability) is associated with another variable (such as poverty). It is calculated by measuring the likelihood of an outcome occurring in a group that has the characteristic of interest compared with its likelihood in a group that does not have the characteristic.

As an example, an OR of 4.3 when comparing poverty between people with and without disabilities, tells us that people with disabilities are 4.3 times as likely as people without disabilities to be living in poverty. A confounder is a factor that is associated with both the outcome and exposure being studied. For example, in the relationship between work status and disability, older people are more likely to have

a disability and older people are less likely to be working. It is important to adjust for confounders to give a more accurate estimate of the association between the exposure and outcome of interest.

Confidence intervals (CI) indicate the precision of a study measurement (such as mean, OR). For a given level of certainty (normally set to 95 per cent), confidence intervals provide a range of values around the sample's estimate that are likely to contain the "true" value of that measure across the entire population. For example, if the prevalence of disability in our study sample is 22.2 per cent (95 per cent CI: 20.5-25.5 per cent), that means we are 95 per cent confident that the "true" prevalence in the entire population is 20.5-25.5 per cent.

Appendix 3

Characteristics of older people with disabilities interviewed in Tanzania and Ukraine

	Tanzania n (%)	Ukraine n (%)
Sex		
Male	10 (45%)	14 (46%)
Female	12 (55%)	17 (54%)
Age		
60-69 years	6 (27%)	9 (29%) ^a
70-79 years	6 (27%)	10 (32%)
80+ years	10 (45%)	11 (35%)
Camp (Tanzania)		
Nduta	11 (50%)	–
Mtendeli	11 (50%)	–
Region (Ukraine)		
Luhansk	–	14 (46%)
Donetsk	–	17 (54%)
Severity of disability^b		
Some problem in at least two domains	4 (18%)	8 (26%)
A lot of problem/cannot do (at least one domain)	18 (82%)	23 (74%)
Disability type^{bc}		
Vision	8 (36%)	9 (29%)
Hearing	3 (14%)	9 (29%)
Mobility	11 (50%)	17 (55%)
Intellectual	5 (23%)	5 (16%)
Multiple domains ^d	11 (50%)	14 (45%)

a. Age data was missing for one participant.

b. Based on responses to Washington Group short set of questions.

c. Sub-totals are >100% because some participants had difficulties in multiple domains.

d. Reported difficulty with more than one domain of functioning.

Appendix 4

Interview guide for older persons

These questions should be used to guide discussion but do not have to be used in the sequence listed below. Not all questions will be relevant to all people. The interviewer should follow up on any additional issues that may arise and seem important in relation to the change to issues that emerge.

Note: Questions reflecting on their experience compared to others: compare to younger people and/or people without disabilities

1. Background on the household, person and family and daily life of the participant

A. Please tell me about your house e.g.

- Rooms, amenities, structure, permanence, toilet facilities
- Who lives with you in this dwelling?
- How long have you lived here?
- How do you feel about living here? (safety)

B. Can you tell me about a typical day for you?

- What do you spend your time doing?
Media (radio/TV)?
- Where? With whom?
- Time spent with others or alone?
- How?

C. Tell me about your family and friends

- Number of family members
- Where do they live?
- Friends/family location (close to home, far away?)
- Do they visit often?
- Do you visit them?

2. Background on the person and her or his impairment or disability

A. Can you tell me about your disability/impairment/difficulty

- When did you first notice the disability/difficulties? (How long has it been?)
- What happened when you first noticed this? How did you feel?
- What (if any) medical/rehab/other services/assistive devices have you sought because of this condition?
 - Are you still receiving these services if you need them?
 - If not, why?

B. How does this condition impact on your daily life (at home/in community)?

- Prompts: Activities, mental health (sad/lonely), accessing services, relationships (friends/family/volunteers), communications.
- Is there anything that is more difficult for you because of your age and/or disability?

C. What would help you look after yourself?

D. Do you feel you are treated differently because of your age/disability?

3. Experience of the humanitarian crisis, requirements, challenges

A. Can you tell us about what happened when you had to leave your home? Prompts: able to leave with others, journey. Was your experience similar or different to others? How? Why? (impact of age/disability)?

B. Mental health

- In the last month have you felt anxious or depressed because of the things you have been through?
- Difficulties sleeping? (how often?)
- What do you think are the causes of these feelings?
- Have you sought help for these feelings?

If not already mentioned – explore specific areas:

C. Shelter and water, sanitation and hygiene

- Please can you describe your dwelling (rooms, amenities, structure, permanence, toilet facilities).
- Do you feel you have the level of privacy that you would like?

D. Primary healthcare

(Ask for before and after the crisis)

- If you get sick and need healthcare, what do you do?
- Prompts: where do you go for treatment?
- Do you face any challenges seeking healthcare (transport, physical access, attitudes of staff)?
- What helps you to access healthcare (transport, family, finances, proximity, assistive device).
- How do your experiences compare to other younger members of your household?

E. Community/social support

- What community or social activities do you take part in?
- What activities would you like to do?
- Is this different from before the conflict?

F. Income

- Can you tell us about your sources of income?
- Probes: pension, disability allowances, relatives, work.
- How do you access this?
- Challenges in receiving?
- How far does this cover your basic requirements (heat, water, food, mobility aids, etc)?
- What do you do if this is not enough?
- Has your level of income changed since before the conflict?

G. Livelihoods

- Who in the house works/engages in income-generating activities? Do you?
- If yes, can you tell us more about this.
- Are there any difficulties?
- Does age/disability impact on your ability to work in any way?

H. Unpaid activities

- Do you engage in any unpaid or volunteer activities?
- Has this changed since the conflict?

I. Food

- Can you tell us about the main sources of food for your family?
- What are the main challenges you face in accessing food – currently and before the conflict?

Available response mechanisms

J. Can you tell us about any formal help (government, NGO, pension, etc) that you are receiving currently or have received in the past? What is your experience of this? Prompts: accessibility, attitudes of staff, impact (positive and negative), challenges compared to others?

K. Are there other aids or services you are aware of that you could benefit from? If yes, what are the reasons you are not receiving this? Is this different for you compared to others?

L. Are you aware of any health or rehabilitation services available to you?

M. What other services or support do you feel you need?

N. How do you access information about aid/relief/services/activities? Is this information equally available to everyone who needs it?

O. Have you been consulted about your needs in humanitarian response/aid activities? Would you like to be? What suggestions would you make for people in your situation?

Services and recommendations

P. What would be of most help to your family? And to you specifically? Prompts: health, rehabilitation, nutrition, shelter, protection, food, livelihoods.

Q. What information would be helpful to you in this situation?

R. How should the information be communicated?

- Services available
- Information on disaster

4. Is there anything else we haven't covered about your experiences you would like to tell me about today?

Appendix 5

Interview guide for family members

Note: Questions reflecting on their experience compared to others: compare to younger people and/or people without disabilities

Background on the household, person and their impairment

1. Can you tell me about your family? Prompts: Who lives in the house, who goes out to work, who is the head of the household.
2. Can you tell me what you know about [Name]'s disability/impairment/difficulty? What do you think caused this condition? Are they accessing any medical or rehabilitation services? How has it helped? If not, why?
3. How do you think this condition or their age impacts on their daily life? What things do they find more difficult or unable to do that other people in the household do?
4. How does this impact on the lives of other people in the family? Prompts: additional caring required, impact on livelihoods, resources, financial, shelter, communication, relationships, wellbeing, inclusion in the community (social inclusion).
5. Who within the family provides support?

Experience of the humanitarian crisis, requirements, challenges

6. Can you tell us about what happened when you had to leave your home? Did all members of the family leave together? What happens to older people with disabilities when they have to leave?
7. What are the major challenges you think [Name] faces in their everyday life? How do these compare to other younger people and people without a disability? What are the things that help them to cope?

8. What do you think are the specific requirements [Name] has that are different to other people in the household/family?

9. What are the barriers and challenges that [Name] faces in accessing needed services or external support? How do these differ from other people in the household?

10. Can you tell us about any aid programmes your family are currently receiving or have received in the past (give context-specific examples)? Are all people in the household able to access these equally? Is [Name] able to access them in the same way? If not, why not?

11. Are there other aid programmes you are aware of that [Name] could benefit from but is not receiving (give context specific examples)? If yes, what are the reasons they are not receiving this? Is this different compared to others in the household?

If not already mentioned – explore specific areas:

12. Primary healthcare: If people in your household get sick and need healthcare, what do you do? Is this the same or different for [Name]? Why?

13. Livelihoods: Who in the house works/engages in income-generating activities? Do you? If yes, can you tell us more about this? What do you like? What are the difficulties? Does [Name]'s age/disability impact on the labour activities for the family in any way?

14. Income: What are the sources of income for your family? And for [Name] specifically? To what extent do these cover the basic requirements for [Name]?

15. What would be of most help to your family? What about to [Name] specifically? Prompts: health, rehabilitation, nutrition, shelter, protection, food, livelihoods.

Is there anything else you would like to tell me about today?

Appendix 6

Interview guide for key informants

These questions should be used to guide discussion but do not have to be used in the sequence listed below. Not all questions will be relevant to all organisations. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues that emerge.

Organisation-specific questions

1. Can you briefly describe the work you and your organisation does?

(Or: Tell me a little bit about the work your organisation does)

2. Please can you describe your organisation and its main objectives and activities in relation to disability and older people in humanitarian crises?

- Activities: e.g. activities that address specific requirements of older people and people with disabilities and activities that are designed to be inclusive of older people with disabilities.
- Policy: Specific policies on inclusion of older people with disabilities
- Guidelines: Guidelines addressing the specific requirements of, or the inclusion of older people with disabilities?

3. How does your organisation collaborate with the government or any other organisation in delivering services to older people with disabilities in humanitarian crises? Is the collaboration formal or informal?

4. How accessible are your programmes/activities/services for older people with disabilities? What challenges do you face in making programmes accessible?

- Human resources
- Financial
- Technical capacity
- Attitudinal

5. Are there any mechanisms in place to involve or consult with older people and people with disabilities in development of programmes/activities/services?

- Information/communication – do you provide large print?
- Physical environment/ buildings – do you ensure all buildings are accessible?
- Attitudinal
- Can you give specific examples of the advantages of involving older people and people with disabilities in programme development?

6. Has anyone in your organisation received any training about older people and people with disabilities? What did the training involve?

7. Does your organisation record data on the age of the people you are seeking to assist? Does your organisation collect information on disability status? If yes, how?

- What does your organisation do with this data?
- Do you collect data on longer-term health conditions of older people?

Experiences of older people with and without disabilities: requirements and access to services

8. What do you think are the specific requirements of older people without disabilities in these refugee camps? Prompts: health; mental health; protection; water, sanitation and hygiene; shelter and non-food items; nutrition; food security; livelihood; access to information.

9. What do you think are the specific requirements of older people with a disability? Prompts (as above).

10. What do you think are the specific challenges experienced by older people with disabilities in this context?

11. What factors or mechanisms aid older people with and without disabilities in accessing needed services or response activities?

- How well does the health system meet the requirements of older people with and without disabilities (e.g. primary healthcare and impairment-specific services)?
- How well do the social protection systems meet the requirements of older people with and without disabilities (pensions, disability allowance)? What are the challenges?
- How well do other response activities meet the requirements of older people with disabilities? Prompts (as above).
- Are there government initiatives or projects in place that aid older people with disabilities in accessing needed services?
- What programmes do other organisations have that aid older people living with disabilities to access the needed services?

12. What are the barriers and challenges that older people living with and without disabilities face in accessing the needed services or aid?

- How accessible are services and infrastructure in the area?
- Do older people have knowledge of the services available to them?

13. In your opinion, what projects should be implemented to support older people with disabilities in humanitarian crises? What do you think are the main challenges and issues in providing these services?

Do you have anything to add?

Appendix 7

Published papers and reports included in the literature review

Author/ Date	Title	Source Paper/Reports	Income level group	Study country	Disability type	Emergency type	Method	Study focus
Godfrey et al ⁸⁰ 1989	<i>Health needs of older adults displaced to Sudan by war and famine: questioning current targeting practices in health relief</i>	P	Low	Sudan	General	Conflict, displaced populations	Mixed	Experiences of older people
HelpAge International ⁸¹ 2006	<i>Rebuilding lives in longer-term emergencies: Older people's experience in Darfur</i>	R	Low	Sudan	General	Conflict, displaced populations	Qualitative	Experiences of older people
HelpAge International and Handicap International ⁸² 2007	<i>Strong and Fragile: learning from older people in emergencies 2007</i>	R	Low	Global, Pakistan, Uganda	General	Natural and conflict	Qualitative	Experiences of older people
Women's Refugee Commission ⁸³ 2008	<i>Disabilities among refugees and conflict affected populations</i>	R	Low	Jordan, Nepal, Ecuador, Kenya, Bhutan	General	Conflict, displaced populations	Qualitative	Experiences of people with disabilities
HelpAge International and Handicap International ⁸⁴ 2014	<i>Hidden Victims of the Syrian Crises: disabled, injured and older refugees</i>	R	Low	Jordan, Lebanon (Syrian refugees)	General	Conflict, displaced populations	Quantitative	Experiences of older people and people with disabilities
Strong, et al ⁸⁵ 2015	<i>Health status and health needs of older refugees from Syria in Lebanon</i>	P	Low	Lebanon	General	Conflict, displaced populations	Mixed	Experiences of older people
HelpAge International ⁸⁶ 2016	<i>Older voices in humanitarian crises: calling for change</i>	R	Low	Lebanon, South Sudan, Ukraine	General	Conflict, displaced populations	Qualitative	Experiences of older people
HelpAge International, CBM, National Disaster Risk Reduction Centre Nepal ⁸⁷ 2016	<i>Assessing the impact of Nepal's 2015 Earthquake on older people and persons with disabilities</i>	R	Low	Nepal	General	Natural (earthquake)	Mixed	Experiences of older people and people with disabilities
Hayes et al ⁸⁸ 2009	<i>Floods in 2007 and older adult services: lessons learnt</i>	P	High	UK	Intellectual	Natural (floods)	Quantitative	Psychosocial function among older people with intellectual disabilities

Appendix 7

Continued

Author/ Date	Title	Source Paper/Reports	Income level group	Study country	Disability type	Emergency type	Method	Study focus
Furukawa et al ⁸⁹ 2012	<i>Exacerbation of dementia after the earthquake and tsunami in Japan</i>	P	High	Japan	Intellectual	Natural (earthquake and tsunami)	Quantitative	Older people with intellectual disabilities
HelpAge International ⁹⁰ 2013	<i>Displacement and older people. The case of the Great East Japan Earthquake and Tsunami of 2011</i>	R	High	Japan	General	Natural (earthquake)	Quantitative	Experiences of older people
Christensen et al ⁹¹ 2013	<i>Seeking safety: Predictors of hurricane evacuation of community-dwelling families affected by Alzheimer's disease or a related disorder in South Florida</i>	P	High	USA	Intellectual	Natural (hurricane)	Quantitative	Preparedness among older people with intellectual disabilities
Good et al ⁹² 2016	<i>Disoriented and Immobile: The Experiences of People with Visual During and After the Christchurch, New Zealand, 2010 and 2011</i>	P	High	New Zealand	Visual impairment	Natural (earthquake)	Qualitative	Experiences of older people with visual disabilities
Akanuma et al ⁹³ 2016	<i>Disturbed social recognition and impaired risk judgement in older residents with mild cognitive impairment after the Great East Japan earthquake of 2011: The Tome project</i>	P	High	Japan	Intellectual	Natural (earthquake)	Quantitative	Psychosocial function among older people with intellectual disabilities

Appendix 8:

Prevalence of disability among older people by age and sex

	Cameroon n=429 (95% CI)	Guatemala n=1148 (95% CI)	India n=352 (95% CI)
Overall prevalence	24.9% (19.5-31.3)	22.4% (19.5-25.4)	39.2% (34.1-44.5)
Age			
60-69 years	15.0% (10.1-21.7)	15.6% (12.5-19.1)	29.9% (23.7-37.0)
70-79 years	28.9% (21.1-38.2)	22.7% (18.1-28.1)	55.6% (45.6-65.3)
80+ years	38.9% (28.4-50.5)	47.8% (39.3-56.5)	65.5% (46.6-80.4)
Sex			
Male	25.5% (18.6-34.1)	20.7% (17.3-24.5)	31.6% (25.6-38.3)
Female	24.5% (18.5-31.7)	23.9% (20.4-27.9)	46.4% (39.1-53.8)

Prevalence of significant limitations by functional domain*

Total	24.9% (19.5-31.3)	22.4% (19.5-25.4)	39.2% (34.1-44.5)
Seeing	9.3% (6.5-13.2)	9.2% (7.5-11.3)	13.6% (10.2-18.1)
Hearing	6.0% (0.4-10.5)	6.3% (4.8-8.2)	13.6% (9.7-18.8)
Mobility	14.0% (10.3-18.7)	13.7% (11.4-16.4)	19.3% (15.4-23.9)
Communication	0.5% (0.1-0.2)	2.3% (1.5-3.5)	2.6% (1.4-4.7)
Cognition	7.5% (5.9-11.1)	5.7% (4.3-7.6)	2.6% (1.2-5.3)
Self-care	3.0% (1.7-5.3)	5.2% (4.1-6.6)	8.0% (5.3-11.6)
Upper body	4.4% (2.6-7.4)	7.8% (6.2-9.6)	10.5% (7.7-14.3)
Anxiety	3.2% (2.0-5.3)	5.5% (4.1-7.3)	7.4% (4.6-11.7)
Depression	2.8% (1.5-4.9)	4.0% (3.0-5.4)	6.5% (3.9-10.8)

*Proportion who reported “a lot of problem/cannot” in each domain. CI = confidence intervals.

Appendix 9:

Comparison of people with ('cases') and without disabilities (control): Demographic and economic characteristics

	Cameroon			Guatemala			Haiti		
	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)
Number	191	66		210	78		47	26	
Age									
60-69	24%	50%	Baseline	38%	55%	Baseline	49%	65%	Baseline
70-79	41%	35%	2.5 (1.3-4.8)	33%	37%	1.3 (0.7-2.3)	28%	23%	1.6 (0.5-5.2)
80+	35%	15%	5.0 (2.2-11.4)	29%	8%	5.5 (2.2-13.8)	23%	12%	3.0 (0.7-12.6)
Sex									
Male	42%	42%	Baseline	47%	45%	Baseline	34%	31%	Baseline
Female	58%	58%	1.2 (0.7- 2.2)	53%	55%	1.0 (0.6-1.7)	66%	69%	0.7 (0.2-2.9)
SES									
1st (poorest)	25%	36%	Baseline	25%	27%	Baseline	18%	25%	Baseline
2nd	31%	14%	3.6 (1.5- 8.7)	27%	32%	0.8 (0.3-1.6)	27%	21%	1.2 (0.2-5.9)
3rd	24%	26%	1.5 (0.7- 3.2)	24%	19%	0.7 (0.4-1.6)	33%	17%	2.6 (0.5-12.5)
4th (richest)	20%	24%	1.5 (0.7- 3.3)	25%	22%	1.1 (0.5-2.5)	22%	38%	0.7 (0.2-3.1)
Education									
None	84%	80%	Baseline	57%	55%	Baseline	41%	40%	Baseline
Some	16%	20%	1.1 (0.5- 2.4)	43%	45%	(0.5-1.6)	59%	60%	0.7 (0.2-2.1)
Literacy									
Literate	22%	20%	Baseline	95%	96%	Baseline	72%	80%	Baseline
Not literate	78%	80%	0.6 (0.3- 1.3)	5%	4%	1.0 (0.5-1.8)	27%	20%	0.6 (0.5-2.6)
Marital status									
Married	65%	62%	Baseline	37%	36%	1. Baseline	33%	32%	Baseline
Widow/divorced	32%	37%	0.6 (0.3- 1.2)	20%	24%	1.0 (0.5-1.8)	41%	44%	0.7 (0.2-4.0)
Not married	3%	2%	–	43%	40%	0.8 (0.2-2.9)	26%	24%	1.3 (0.2-4.0)
Work									
Work past week	41%	72%	0.3(0.2-0.6)*	18%	44%	0.4 (0.2-0.7)	11%	34%	0.2 (0.1-0.9)
Work past year	66%	88%	0.4(0.2-0.8)*	26%	52%	0.5 (0.3-0.9)	19%	42%	0.4 (0.1-1.1)

Note: Definition of work varied in the different settings: in India and Cameroon this included work done on own land, but this was not included in other settings. CI = confidence intervals.

Appendix 9

Continued

	India			Nepal			Palestine		
	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)
Number	199	63		86	84		794	3577	
Age									
60-69	55%	76%	Baseline	49%	47%	Baseline	34%	60%	Baseline
70-79	32%	24%	1.9 (0.9-3.6)	24%	35%	0.7 (0.4-1.5)	37%	28%	2.3 (1.9-2.8)
80+	14%	0%	N/A	28%	17%	1.7 (0.8-3.8)	29%	12%	4.4 (3.6-5.4)
Sex									
Male	46%	44%	Baseline	51%	55%	Baseline	35%	46%	Baseline
Female	54%	56%	1.0 (0.5-1.7)	49%	45%	1.2 (0.6-2.2)	65%	54%	1.5 (1.2-1.7)
SES									
1st (poorest)	27%	26%	Baseline	47%	35%	Baseline	N/A	N/A	
2nd	24%	28%	0.9 (0.4-1.9)	21%	29%	0.5 (0.2-1.1)			
3rd	24%	22%	1.1 (0.5-2.7)	16%	26%	0.5 (0.2-1.1)			
4th (richest)	24%	22%	1.0 (0.4-2.3)	16%	11%	1.2 (0.5-3.2)			
Education									
None	87%	85%	Baseline	83%	75%	Baseline	64%	39%	Baseline
Some	13%	15%	0.7 (0.3-1.8)	17%	25%	0.7 (0.3-1.8)	36%	61%	0.6(0.5-0.7)
Literacy									
Literate	21%	17%	Baseline	24%	39%	Baseline	36%	61%	Baseline
Not literate	79%	83%	1.4 (0.6-3.1)	76%	61%	2.1(0.9-4.7)	64%	39%	1.9 (1.6-2.3)
Marital status									
Married	75%	77%	–	61%	74%	Baseline	46%	67%	Baseline
Widow/divorced	25%	23%	0.9 (0.4-2.0)	34%	25%	1.6 (0.8-3.3)	49%	29%	1.6(1.3-2.0)
Not married	1%	0%	–	6%	1%	–	5%	4%	1.6 (1.1-2.4)
Work									
Work past week	26%	66%	0.2 (0.1-0.4)	11%	30%	0.3 (0.1-0.6)	2%	13%	0.2 (0.1-0.3)
Work past year	30%	69%	0.2 (0.1-0.4)	16%	36%	0.3 (0.1-0.7)	–	–	–

Note: Definition of work varied in the different settings: in India and Cameroon this included work done on own land, but this was not included in other settings. CI = confidence intervals.

Appendix 10:

Mean participation restriction score among older people with and without disabilities*

Without or with disabilities >	Cameroon			Guatemala			Haiti			India		
	Without	With	P value	Without	With	P value	Without	With	P value	Without	With	P value
Self-care	93.6	87.9	0.06	95.6	84.4	0.01	99.6	90.7	0.01	96.1	75.1	<0.001
Domestic life	89.5	72.7	<0.001	88.0	61.9	<0.001	93.5	66.6	<0.0001	86.1	55.4	<0.001
Interpersonal behaviours	91.7	82.3	0.002	91.7	77.8	0.001	96.2	85.4	0.008	86.9	71.9	<0.001
Major life areas	73.4	62.2	0.05	71.2	44.8	<0.001	82.2	50.2	<0.001	67.5	42.9	<0.001
Community, social and civil life	81.4	71.1	0.01	90.0	62.7	<0.001	88.5	74.7	0.05	73.8	49.4	<0.001

*Lower scores denote greater participation restrictions.

Appendix 11:

Proportion of older adults with (cases) and without (controls) disabilities reporting that different aspects of the environment were a “big problem” in terms of creating a barrier to participation in activities that matter to them

	Cameroon			Guatemala			Haiti			India		
	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)	Cases	Controls	OR (95% CI)
Transport	33%	11%	4.4 *(1.9-10.6)	29%	14%	2.4 *(1.2-5.0)	36%	27%	1.3 (0.4-4.2)	36%	13%	4.1 *(1.8-9.3)
Natural environment	28%	8%	5.1 *(1.9-13.6)	25%	9%	3.6 *(1.5-8.4)	26%	19%	1.4 (0.4-4.7)	20%	8%	3.2 *(1.2-8.6)
Surroundings	8%	5%	2.1 (0.6 - 7.8)	23%	9%	3.1 *(1.3-7.2)	17%	12%	-	15%	5%	4.1 *(1.2-14.2)
Format of information	4%	3%	1.3 (0.2-6.9)	19%	9%	2.2 (0.9-5.1)	12%	4%	-	16%	0%	-
Availability of healthcare services	24%	8%	3.6 *(1.3-9.6)	35%	28%	1.4 (0.8-2.5)	35%	16%	-	29%	6%	6.5 (2.2-19.1)
Availability of assistance at home	13%	5%	2.9 (0.8-10.1)	18%	15%	1.4 (0.7-2.9)	11%	17%	-	31%	3%	15.5 *(3.6-66.6)
Availability of assistance at work	4%	0%	-	12%	3%	6.2 *(1.4-27.5)	0%	0%	-	13%	2%	-
Other people's attitudes (at home)	4%	2%	3.5 (0.4-29.3)	10%	9%	1.5 (0.6-3.8)	16%	11%	-	18%	3%	-
Other people's attitudes (at school/work)	3%	0%	-	6%	3%	3.8 (0.8-17.7)	0%	0%	-	10%	0%	-
Prejudice and discrimination	3%	0%	-	12%	12%	1.2 (0.5-2.7)	11%	8%	-	11%	0%	-
Policies and rules (organisations)	2%	0%	-	2%	3%	1.3 (0.2-6.9)	0%	0%	-	9%	0%	-
Government programmes and policies	2%	2%	2.0 (0.2-19.8)	6%	4%	1.5 (0.4-5.7)	13%	12%	1.2 (0.2-8.6)	24%	8%	4.0 (1.5-10.8)

Note: Cases = Older adults with disabilities. Control = older adults without disabilities. *statistically significant difference between people with and without disabilities = cell sizes too small for calculation of odds ratio. CI = confidence intervals.

Glossary

Assistive devices

Assistive devices and technologies are those whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall wellbeing. They can also help prevent impairments and secondary health conditions. Examples of assistive devices and technologies include wheelchairs, prostheses, hearing aids, visual aids, and specialised computer software and hardware that increase mobility, hearing, vision, or communication capacities. In many low-income and middle-income countries, only 5-15 per cent of people who require assistive devices and technologies have access to them.

Source: World Health Organization and the World Bank, *World report on disability*, Geneva, WHO, 2011, Chapter 2, <http://bit.ly/2jFpXDh>

Barriers

Barriers are factors that prevent a person from having full and equal access and participation in society. These can be environmental, including physical barriers (such as the presence of stairs and the absence of a ramp or an elevator) and communication barriers (such as only one format being used to provide information), attitudinal barriers (such as negative perceptions of older people or people with disabilities) and institutional barriers (such as policies that can lead to discrimination against certain groups). Some barriers exist prior to the conflict or natural disaster; others may be created by the humanitarian response.

Source: *Humanitarian inclusion standards for older people and people with disabilities*, CBM International, HelpAge International and Humanity & Inclusion, London, 2018, p251, www.helpage.org/download/5a7ad49b81cf8

Caregivers

Adults or children who provide support to people who are no longer able to do the basic tasks of daily life without assistance. They may provide care informally (as a relative, friend or neighbour) or formally (as a professional worker). Their support is often unpaid.

Enablers

For the purpose of this research, enablers are the factors that facilitate access and participation in society for older people with disabilities.

Impairment

A significant deviation or loss in body functioning or structure. Impairments may be either temporary or permanent, and people may have multiple impairments.

Sources: United Nations Children's Fund (UNICEF), General Guidance: Including children with disabilities in humanitarian action, UNICEF, 2017, <http://bit.ly/2zjrqtJ>; citing: World Health Organization, *Towards a Common Language for Functioning, Disability and Health ICF*, WHO, 2002, www.who.int/classifications/icf/en

Incentive workers

In many contexts, refugees are engaged as “incentive workers” to undertake jobs in connection with the provision of assistance and services to the displaced community, both within and outside camps. Such work is often characterised as volunteering rather than employment and the compensation described as an “incentive”.

Source: Which side are you on? Discussion paper on UNHCR's policy and practice of incentive payments to refugees, December 2014, www.unhcr.org/5491577c9.pdf

Inclusion

A rights-based approach to community programming, aiming to ensure that persons with disabilities have equal access to basic services and a voice in the development and implementation of those services. At the same time, it requires that mainstream organisations make dedicated efforts to address and remove barriers.

Source: International Federation of Red Cross and Red Crescent Societies, *All Under One Roof: Disability-inclusive shelter and settlements in emergencies*, Geneva, IFRC, 2015, p10, <http://bit.ly/2Bt4FCZ>

Intersectionality

The interaction of multiple factors, such as disability, age and gender, which can create multiple layers of discrimination, and, depending on the context, entail greater legal, social or cultural barriers. These can further hinder a person's access to and participation in humanitarian action, and, more generally, in society.

Source: *Humanitarian inclusion standards for older people and people with disabilities*, CBM International, HelpAge International and Humanity and Inclusion, London, 2018, p253, www.helpage.org/download/5a7ad49b81cf8

Protection

Protection encompasses all activities aimed at ensuring full respect for the rights of the individual in accordance with the letter and the spirit of the relevant bodies of law, i.e. human rights law, international humanitarian law and refugee law. Human rights and humanitarian organisations must conduct these activities in an impartial manner (not on the basis of race, national or ethnic origin, language or gender).

Source: Professional Standards for Protection Work carried out by humanitarian and human rights actors in armed conflict and other situations of violence, ICRC, Geneva, 2009, p8, <https://shop.icrc.org/publications/professional-standards-for-protection-work-carried-out-by-humanitarian-and-human-rights-actors-in-armed-conflict-and-other-situations-of-violence.html>

Older people

Older people are a fast-growing proportion of the population in most countries, but are often neglected in humanitarian action. In many countries and cultures, being considered old is not necessarily a matter of age, but is linked to circumstances, such as being a grandparent or showing physical signs of ageing, such as white hair. While many sources use the age of 60 and above as a definition of old age, 50 years and over may be more appropriate in many of the contexts where humanitarian crises occur.

Source: *Humanitarian inclusion standards for older people and people with disabilities*, CBM International, HelpAge International and Humanity & Inclusion, London, 2018, p254, www.helpage.org/download/5a7ad49b81cf8

Older people's associations (OPAs)

Older people's associations are innovative community-based organisations of older people, aimed at improving the living conditions of older people and developing their communities. They utilise the unique resources and skills older people have, to provide effective social support, facilitate activities and deliver services.

Source: HelpAge International, *Older people in community development: The role of older people's associations (OPAs) in enhancing local development*, London, HelpAge International, 2009, p2, <http://bit.ly/2kczch1>

Organisations of people with disabilities, or disabled people's organisations (DPOs)

Disabled people's organisations are usually self-organised organisations where the majority of control at board level and at membership level is with people with disabilities. Their role is to provide a voice of their own, on all matters related to the lives of people with disabilities.

Source: CBM, *Disability Inclusive Development Toolkit*, Bensheim, CBM, 2017, <http://bit.ly/2lVei5A>

People with disabilities

People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Source: UN General Assembly, Convention on the Rights of Persons with Disabilities (A/RES/61/106), Article 1, <http://bit.ly/2ieddTM>

Vulnerability

The conditions determined by physical, social, economic and environmental factors or processes which increase the susceptibility of an individual, a community, assets or systems to the impacts of hazards.

Source: United Nations Office for Disaster Risk Reduction, Terminology, <http://bit.ly/2tcCgPM> (11 December 2017)

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Philip Sheppard/LSHTM

Find out more:

www.helpage.org/missingmillions

HelpAge International
PO Box 70156, London WC1A 9GB, UK
Tel +44 (0)20 7278 7778
info@helpage.org
www.helpage.org

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