



Executive summary

# Missing millions:

*How older people with disabilities are excluded from humanitarian response*

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## **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 Ndotu 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 6 and 7.

## 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.



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## 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
<b>Livelihoods and social protection</b>	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><b>Physical:</b> Distance to banks, lack of affordable transport, inaccessible buildings</p> <p><b>Institutional:</b> Requiring displaced people to present themselves for verification purposes, denying disability pensions to those with a living relative, exclusion from livelihood programmes</p> <p><b>Attitudinal:</b> Stigma associated with disability and pension distribution systems</p> <p><b>Financial:</b> 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>
<b>Protection: Safety and evacuation from danger</b>	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><b>Physical:</b> Distance, terrain, lack of accessible evacuation routes</p> <p><b>Financial:</b> Cost of accessible transport</p> <p><b>Information:</b> 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>
<b>Healthcare and rehabilitation (medications, access to facilities)</b>	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><b>Financial:</b> Direct and indirect costs of medication, other general health and impairment-specific interventions</p> <p><b>Physical:</b> Inaccessible/unaffordable transport, stairs, nowhere to lie down, long queues</p> <p><b>Attitudinal:</b> 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>
<b>Access to food and other essential non-food items</b>	<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><b>Physical:</b> Distance, difficulty carrying rations, crowded distribution sites</p> <p><b>Institutional:</b> For example, being required to be physically present, lack of priority being given, invisibility; closure of organisations providing humanitarian assistance</p> <p><b>Financial:</b> 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
<b>Accessible/ adapted shelter</b>	Older people with disabilities are at greater risk of negative effects of basic and inaccessible shelter.	<b>Physical:</b> Inaccessible infrastructure (stairs, lack of ramps); inaccessible toilets; lack of household items (such as mattresses) <b>Financial:</b> 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
<b>Dignity</b>	Older people with disabilities experience negative impact on dignity.	<b>Physical:</b> Lack of privacy in shelters, inaccessible latrines and houses <b>Institutional:</b> Inaccessible social pensions systems	
<b>Independence, social interaction and participation</b>	Older people with disabilities are more likely to face social isolation. They are less likely to participate in social activities outside the house.	<b>Physical:</b> Lack of transport, distance, inaccessible homes, toilets and public buildings, infrastructure destroyed by disaster; lack of assistive devices <b>Attitudinal:</b> 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.
<b>Protection from theft and discrimination</b>	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).	<b>Attitudinal:</b> 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
<b>Psychological health</b>	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



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Read the full report at:

[www.helpage.org/missingmillions](http://www.helpage.org/missingmillions)

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

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