

**Submission by HelpAge International on the rights of older persons with disabilities**

**Question 3: Please provide information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the realization of the rights of older persons with disabilities**

**The rights of older persons with disabilities in humanitarian responses**

Article 11 of the Convention on the Rights of Persons with Disabilities commits States Parties to taking all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

*Up to 14 million older persons with disabilities may be affected by humanitarian disasters, yet the humanitarian sector is paying limited attention to the intersections between disability and ageing and the rights of older persons with disabilities are widely overlooked in humanitarian responses.*

*A study conducted by HelpAge International and the London School of Hygiene and Tropical Medicine in 2018 investigated the specific experiences of older persons with disabilities affected by humanitarian crises, with a focus on older persons with disabilities in Tanzania and Ukraine. An executive summary and the full report are available at* [*https://www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/*](https://www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/)

*The study found older persons with disabilities face particular barriers to the enjoyment of their rights in humanitarian responses in the following ways:*

**Right to humanitarian assistance**

The intersections between disability and age are rarely taken into account in humanitarian responses**.**

* Core humanitarian guidance and standards, for example the Sphere Handbook[[1]](#footnote-1) and Core Humanitarian Standards[[2]](#footnote-2) do not provide specific analysis and guidance on older persons with disabilities. The Charter on Inclusion of Persons with Disabilities in Humanitarian Action[[3]](#footnote-3), however, emphasises the need to consider the intersection of disability and other characteristics, including age, and states the importance of disaggregating disability data by age.
* Training of humanitarian staff fails to take the intersection of ageing and disability into consideration. In the HelpAge and LSHTM 2018 study [hereafter the study], representatives of international organisations highlighted several current staff training initiatives to promote age and disability inclusion[[4]](#footnote-4) which typically focused either on disability inclusion, or on people with disabilities and older people, but did not consider the intersection of disability and ageing.

**Non-discrimination and equality**

Older persons with disabilities can be subjected to both systemic discrimination and discriminatory attitudes and behaviour in their daily lives.

* In camps for Burundian refugees in Western Tanzania, in the absence of any social protection schemes, many older persons with disabilities expressed a desire to earn an income, for example, by setting up a small business at home or nearby. While, younger people and persons without disabilities might find work with NGOs or set up small businesses such as shops and market stalls, older persons with disabilities felt they did not have the same opportunities. Key informants in the study also suggested that older persons with disabilities were being excluded from livelihood programmes, which focused on younger adults.

Older persons with disabilities also 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.” 70-year-old woman

* Research by UNHCR in Ukraine found that state services supported single older persons with disabilities who had no children, but not those with children. This can put older persons with disabilities more at risk and force them to become more dependent on their families.[[5]](#footnote-5)

**Exercise of legal capacity**

Restrictive systems in the camps in Tanzania denied older persons with disabilities the right to appoint a trusted person to collect their entitlements, including food and clothing.

**Access to support to live independently in the community**

Older persons with disabilities’ independence can be limited, they can be socially isolated and more restricted from participating in social, community and civic life than older persons without disabilities.

* Refugees in the camps in Tanzania lived in small and often crowded houses made of tarpaulin, brick or mud. Older persons with disabilities who were unable to leave their house suffered from a 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.” 62-year-old man. Some had been given mattresses and blankets, but some had not. Inaccessible toilets were a serious problem with several interviewees saying they could not reach toilets on their own, or had difficulty using them.

Support to participate in the community was often unavailable to older persons with disabilities in Tanzania. Some said it was harder for them to visit friends and take part in social or religious activities or attend camp meetings than older people without disabilities. They said they were physically unable to reach these gatherings, they were too far away 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.” 80-year-old man

* Most older persons with disabilities interviewed in Eastern Ukraine were living in the community. Nonetheless poor housing conditions limited their 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.

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.” 86-year-old woman

**Access to free and affordable healthcare**

Older persons with disabilities can be denied their access to free and affordable health care due to high costs, inaccessible services and negative attitudes of health personnel**.**

* In refugee camps in Tanzania, healthcare is provided free of charge. Most older persons with disabilities in the study said they could reach the hospital in their camp when they needed to. However, they said there was a lack of appropriate medication and they were prescribed treatment they thought was ineffective.
* In Eastern Ukraine older persons who were registered as having a disability said that doctors and nurses would visit them at home but some could not then afford the recommended treatment: “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.’” 83-year-old woman

Older people with disabilities had varied experiences of interacting with healthcare staff. Some spoke positively about doctors making home visits but 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.” 80-year-old man

Hospitals were often inaccessible to older persons with disabilities. Many had no toilets, lifts, or places to lie down in waiting areas. Some 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.” 68-year-old woman

An additional complication for some displaced older persons with disabilities was that they could only receive health services in the area in which they were registered. 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.

**Access to free or affordable rehabilitation goods and services**

Older persons with disabilities can be denied access to the rehabilitation goods and services they require.

* 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.

**Access to social protection schemes**

Older persons with disabilities may not have access to adequate social protection. The low value of entitlements may not be enough for an adequate standard of living. Eligibility criteria can exclude certain older persons with disabilities. Bureaucracy can also result in exclusion. Physical, institutional and attitudinal barriers can also prevent older persons with disabilities access state entitlements.

* Older persons in Ukraine rely on state pensions as their main source of income. All the interviewed said that the pensions and entitlements they received were not enough to meet the basic costs of living, particularly their healthcare needs: “Prices keep rising. The pension doesn’t manage to catch up.” 71-year-old woman

The disability pension 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). Some older persons with disabilities entitled to this pension said they should be placed in a higher category because of the levels of support they required.

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, even if the relative had moved to a new area because of the conflict and no longer lived with them: “The government official came to my room. She told [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 re-settler 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.” 65-year-old man

Bureaucracy means those living in in informal or temporary accommodation can be denied 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.” 87-year-old man

The distribution of the state disability and old-age pensions may not take into account the physical barriers faced by older persons with disabilities who described long journeys to banks, lack of affordable transport and inaccessible buildings. This was 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 older man who had had a leg amputated: “They invented laws saying that re-settlers 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.”

**Right to information**

Older persons with disabilities can be denied access to information in a humanitarian crisis when that information is not in an accessible or appropriate form.

* Two studies from high-income countries highlighted difficulties that older persons with disabilities had with accessing information during earthquakes. Channels such as radio and television were difficult to use by older persons with a visual impairment in New Zealand[[6]](#footnote-6) and older persons with a mild cognitive impairment in Japan[[7]](#footnote-7).

**Right to food**

Restrictive systems in humanitarian responses, such as the requirement to go to distribution points in person, can prevent older persons with disabilities from receiving aid.

* Displaced older persons with disabilities in Tanzania said they faced difficulties collecting food and other items themselves. As a result, some said they did not have enough food and went hungry: “It’s difficult for me to carry my food ration because of my poor health and my disabilities.” 100-year-old woman

**Question 4: Please provide information on the existence of long-term care services in your country and describe to what extent they promote the autonomy and independence of older persons with disabilities.**

* The 2015 ILO report *Long term care protection for older persons: A review* covers 80 per cent of the global population aged 65 and over and finds extreme deficits in long-term care services due to a lack of 13.6 million long term care workers worldwide. It also cites significant concerns about age discrimination in the long-term care sector including unequal treatment of older persons compared to younger people who need long-term care and the fact that impoverishment, exclusion and violence and abuse in long-term care settings rarely result in societal concern or public criticism.[[8]](#footnote-8)
* In a 2017 consultation with 450 older persons across 24 countries[[9]](#footnote-9), many older persons said they had no access to the care and support services they may need to live independent lives. They said that without care and support services, deterioration in their health and a loss of income and work forced them to become dependent on others. Family members were the only care and support providers available to most older people: “There are no support services available to older people in my community. Only family members are taken as or believed to provide assistance with daily activities. But this does not happen for all.” Nepal, 71-year-old woman

The type of care and support services available to older people varied in some respects across regions but in every region older people said care and support services were limited and unaffordable to everyone except those (the older person or their family) with a high income: “[A barrier to accessing care and support is] family members not having enough income to hire a paid carer or to send their parents to a care centre.” Myanmar, group discussion

Many older people said they had little effective choice and control over their support services: “Usually an old person has to put up with the way they are cared for.” Russian Federation, 65-year-old woman

* In a 2019 consultation with 1,063 older persons, of whom 46 per cent were older persons with disabilities, across 10 African and Asian countries[[10]](#footnote-10), 89 per cent of everyone consulted and 89 per cent of those with disabilities said it was very important or important to them to make their own decisions about their care and support services, including decisions involving planning ahead for future support. Despite this, of everyone consulted, 44 per cent said they had no or limited freedom to make such decisions and 58 per cent said they had access to a little or no information at all about their options for care and support services. Ninety-one per cent said they would like to have access to more information.

Giving instructions in advance about future medical treatment or care and support was a new concept to many participants. Only 14 per cent had made any advance instructions and 73 per cent said they had no access to any information about their options to do so. Nonetheless, 82 per cent of everyone consulted and 81 per cent of those with disabilities said it was very important or important to have the opportunity to issue advance instructions: “I can arrange care and treatment services as per my choice.” 75-year-old man, Bangladesh

**Question 7: Please provide information on any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of older persons with disabilities and identify lessons learned from these.**

**Access to assistive technologies**

HelpAge International is inputting into the following initiatives on improving access to assistive technologies to encourage them to address the intersection between ageing and disability:

* WHO Gate[[11]](#footnote-11):
* AtScale2030[[12]](#footnote-12)

HelpAge International is taking measures to facilitate the personal mobility of older persons with disabilities in the manner and at the time of their choice, and at affordable cost, including by:

* Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for all persons with disabilities. HelpAge is working with the WHO Gate initiative to promote the use of the 50 listed assistive aids to ensure older people’s assistive technology needs are included in the policy, product and personnel planning, including through their online training on assistive products and development of policy and personnel pillars.
* Facilitating access by older persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost. HelpAge Pakistan and other partners assess and provide appropriate mobility aids and glasses to improve older persons’ independence in their home and community.
* Providing training in mobility skills to older persons with disabilities and to specialist staff working with persons with disabilities. In Kibondo, Tanzania, rehabilitation staff and social workers have built up a community-based approach to making services accessible in the camp setting and addressing mobility and communication needs.

For further information, please contact Bridget Sleap, bsleap@hepage.org

1. Sphere Project, Sphere Handbook: Humanitarian Charter and Minimum Standards in Disaster Response, 2011, www.refworld.org/docid/4ed8ae592.html [↑](#footnote-ref-1)
2. CHS Alliance, Group URD and the Sphere Project, Core Humanitarian Standard on Quality and Accountability, 2014, https://corehumanitarianstandard.org/files/files/Core%20 Humanitarian%20Standard%20-%20English.pdf [↑](#footnote-ref-2)
3. <https://humanitariandisabilitycharter.org/wp-content/themes/humanitarian-disability-charter.org/pdf/charter-on-inclusion-of-persons-with-disabilities-in-humanitarian-action.pdf> [↑](#footnote-ref-3)
4. For example, UNHCR’s e-learning module on working with people with disabilities and the International Federation of Red Cross and Red Crescent Societies (IFRC) training programme on identifying and addressing discrimination. [↑](#footnote-ref-4)
5. UNHCR, Strengthening Protection of Persons with Disabilities in Forced Displacement: The situation of refugees and internally displaced persons (IDPs) with disabilities in Ukraine, Ukraine, UNHCR, 2016 [↑](#footnote-ref-5)
6. Good G A, Phibbs S and Williamson K, ‘Disoriented and immobile: the experiences of people with visual impairments during and after the Christchurch, New Zealand, 2010 and 2011 earthquakes’, Journal of Visual Impairment & Blindness, 110:6, 2016, p.425-435 [↑](#footnote-ref-6)
7. Akanuma K et al., ‘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’,’ Psychogeriatrics 16:6, January 2016 [↑](#footnote-ref-7)
8. Scheil-Adlung, *Extension of Social Security: Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ILO, ESS Working Paper No. 50, 2015, p.xiii [↑](#footnote-ref-8)
9. HelpAge International, *Freedom to decide for ourselves; What older people say about their rights to autonomy and independence, long term care and palliative care*, 2018

<https://www.helpage.org/newsroom/latest-news/freedom-to-decide-for-ourselves-older-peoples-rights-are-denied-says-new-report/> [↑](#footnote-ref-9)
10. Global Alliance for the Rights of Older People, *Our voices, our rights: What older people say about the normative elements of their right to autonomy and independence*, 2019 [↑](#footnote-ref-10)
11. <https://www.who.int/phi/implementation/assistive_technology/phi_gate/en/> [↑](#footnote-ref-11)
12. <https://atscale2030.org/> [↑](#footnote-ref-12)