

HelpAge International Submission on Long-term care and palliative care

9th Working Session of the Open-ended Working Group on Ageing, 2018

Introduction

Older people must be part of the growing discussion on their human rights. To this end, in November 2017 HelpAge International consulted older people across 24 countries¹ on the rights to be discussed at the 9th Session of the UN OEWG. This submission presents the issues they raised and uses their own words. The 450 participants were self-selecting so their responses are not a representative sample of older people.

Guiding Question 1: Long-term care and support in legal and policy frameworks

There is no explicit standard on the right to support for independent living in older age in international human rights law. Article 19 of the Convention on the Rights of Persons with Disabilities, 2006, which guarantees the right to independent living for persons with disabilities only applies to older persons with disabilities. Some regional human rights standards recognise care and support for independent living in older age. However these vary and are inconsistent across regions.

Guiding question 2: Challenges faced in accessing long-term care and support

It was clear from the consultation responses that many older people have 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 force them to become dependent on others. Family members are 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

Many older people said they have 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

“I have a lot of say, but what my relatives can actually do is limited.” Serbia, man in his seventies

The types of care and support services available to older people vary in some respects across regions but in every region older people said care and support services are limited

¹ Argentina, Bolivia, Cambodia, Chile, Colombia, Costa Rica, Kenya, Kyrgyzstan, Mauritius, Moldova, Mongolia, Myanmar, Nepal, Nigeria, Peru, Philippines, Russian Federation, Rwanda, Serbia, Slovenia, Sudan, Tanzania, Uganda and Zambia

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

Guiding Question 3: Necessary measures to ensure high-quality and sustainable long-term care and support systems

International human rights standards are needed on older people’s right to affordable, appropriate, integrated, quality, timely, holistic, care and support services which are adapted to their individual needs, promote and protect their well-being and maintain their autonomy and independence, without discrimination of any kind.

The right should apply to care and support services in all settings, public and private, including but not limited to in the home, in the community, and in residential settings.

Older people should have the right to the care and support services they require independent of and unrelated to the income of their family members.

States should take steps to ensure, inter alia, older people:

- Enjoy autonomy and independence in the exercise of this right
- Are able to participate fully in the community and society
- Have access to effective complaints and redress mechanisms
- Have access to information about their health status and care and support services

States should ensure that standards and quality of care and support services are in line with human rights principles.

States should ensure that older people are not denied necessary and appropriate care and support services based on their and/or their family’s financial means. States should develop and implement policies to address public and private financing of care and support services.

Guiding Question 5: Palliative care in legal and policy frameworks

There is no explicit standard on the right to palliative care in international human rights law. However, there is a growing body of advisory documents by UN Treaty Bodies and Special Procedures that establish access to palliative care as a right. Some regional human rights standards recognise the right to palliative care. However these vary and are inconsistent across regions.

International human rights standards are needed on older people’s right to quality palliative care services that are available, accessible, and acceptable without discrimination of any kind.

The right should apply to holistic palliative care in all settings, including long-term care and support settings, and should not be limited to pain relief or any particular treatment or setting.

States should take steps to ensure, inter alia:

- Quality palliative care services are available, accessible and acceptable for older people in a setting consistent with their needs, will and preferences, including at home and in long-term care settings
- Availability and accessibility of essential medicines, including internationally controlled essential medicines, for the treatment of moderate to severe pain, and for palliative care of older persons
- A range of supports to exercise legal capacity, including the appointment of one or more trusted persons to assist older people to make decisions based on their instructions, will and preferences, and the opportunity to make advanced directives, living wills and other legally binding documents that set out their will and preferences around medical interventions, palliative care and other support and care at the end of life
- Older people are able to express their free, prior and informed consent to their palliative care treatment and any other health matters
- Training, regulation and monitoring of compliance of all palliative care providers with professional obligations and standards.

Guiding Question 6: Challenges facing older people regarding end-of-life care

It was clear from the consultation responses that many older people have no access to palliative care to help them die free from pain and unnecessary suffering. Palliative care services were limited or non-existent in all countries included in the consultation.

“There isn’t any palliative care in this community.” Cambodia, group discussion

The concept of palliative care was completely new to many older people.

“We didn’t even know such services exist in our country or elsewhere.” Moldova, group discussion

Older people identified high costs and lack of information as the two most common barriers for accessing palliative care where these services were available. Other barriers identified were insufficient and poor quality services, long distances between home and services, long waiting lists and bureaucracy. Some participants said negative attitudes of doctors and medical staff towards older people stopped them from accessing palliative care services. One participant said the services were not available where they wanted to die. Restrictive drug laws were also reported as a barrier.

“In our country, there are very strict laws on the issuance of opioid analgesics. Doctors often do not prescribe them because they are afraid to take the risks.” Kyrgyzstan, group discussion

A full report of the consultation findings will be submitted to the OEWG in advance of the 9th Session and can be found [here](#). For further information contact Bridget Slep, HelpAge International bslep@helpage.org