

What older people say about their rights to autonomy and independence, long-term care and palliative care: key messages

You can use this document:

- To inform your submission to the [OEWG consultation](#)
- To inform your discussions with government and NHRIs in the run-up to the OEWG session
- To inform your contribution to the discussions at the OEWG session.

The consultation: what older people say

The participation of older people in the Open-ended Working Group on Ageing (OEWG) discussions is essential if the outcomes are to reflect their lived experience. Organisations involved in the Age Demands Action campaign and HelpAge Global Network members consulted with 450 older people in 24 countries on their experiences of these rights. Three hundred and fifty were women and 100 were men.¹ Older people's responses in this consultation indicate that many of them do not enjoy their rights in the areas of autonomy and independence, long-term care and palliative care.

Autonomy and independence

The majority of participants said they are being denied their rights to autonomy and independence.

- They said independence was being able to make their own decisions, freely and without interference from other people.
- However they said they are not able to make their own decisions in many areas of their lives including finance, employment, management and disposal of their property, who to vote for, where and with whom to live, access to health services, family life and participation in community, voluntary or social activities.
- Different people prevent, or interfere with, older people's autonomy. This includes government and local authorities, policymakers, local leaders, service providers, and family members.
- A deterioration in health or income, the loss of a job or retirement are all events that currently make older people dependent on others and with that comes a loss of autonomy.
- There are no explicit standards on autonomy and independence in older age in international human rights law.

Long term-care and support services

The majority of participants said they have no choice and control over, or access to, the care and support services they may need to live independent lives.

- In every region long-term care and support services are limited and unaffordable to everyone except those with high-incomes.
- Family members are the only support providers available to most older people.

¹ Participants were self-selecting so their responses cannot be considered to be a representative sample of older people.

- Without support services, loss of income and deterioration in health result in older people's dependency on others.
- There is no explicit standard on the right to support for independent living in older age in international human rights law.

Palliative care

The majority of participants said they have no access to palliative care to die free from pain and unnecessary suffering.

- Palliative care services are limited or non-existent everywhere.
- The concept of palliative care is completely new to many older people.
- There is no explicit standard on the right to palliative care in international human rights law.

Normative framework of older people's rights

A clear articulation of these rights and state obligations towards older people in a new UN convention on the rights of older people is necessary to change this. This should include the following rights:

- Older people have the right to freedom of personal autonomy to make decisions, to determine their life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others.
- Older people have the right to be recognized as rights holders under the law and to take action and make decisions that are legally recognized.
- Older people have the right to support services for independent living, which are adapted to their individual needs, promote and protect their well-being and maintain their autonomy and independence, without discrimination of any kind.
- Older people have the right to palliative care without discrimination of any kind.

Definitions

Autonomy: Autonomy is the ability to make choices and decisions, including with support if necessary, according to one's will and preferences.

Independence: Independence is the ability to perform actions of daily living and participate in society, including with support if necessary, according to one's will and preferences.

Long-term care: *'the activities undertaken by others to ensure that people with a significant on-going loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.'* WHO

Support: Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society.

Palliative care: *'an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.'* WHO

We will release a full report at the end of March. For any questions, please email Bridget Sleap bsleap@helpage.org