



HelpAge

International

Freedom to decide for ourselves

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

Contents

3 Introduction

4 Key findings

5 1. Autonomy and independence

5 1.1 Lack of autonomy in older age

6 1.2 Denial of older people's autonomy

6 1.3 Loss of autonomy in older age

7 1.4 What independence means to older people

8 1.5 Autonomy and independence in human rights law

9 1.6 Recommendations on the right to autonomy and independence

10 1.7 Recommendations on the right to equal recognition before the law

11 2. Long-term care

11 2.1 Care and support available to older people

11 2.2 Care and support providers

12 2.3 Barriers to accessing care and support

13 2.4 Choice and control over care and support

14 2.5 Long-term care in human rights law: care and support for independent living

14 2.6 Recommendations on the right to care and support for independent living

16 3. Palliative care

16 3.1 Palliative care services available to older people

16 3.2 Barriers to accessing palliative care services

17 3.3 Palliative care in human rights law

18 3.4 Recommendations on the right to palliative care

19 Annexes



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

Freedom to decide for ourselves

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

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

Written by Bridget Sleep
Consultation coordinated by Ellie Parravani

Front cover photo by Konrad Stoehr/HelpAge
Deutschland (Ethiopia)

Design by TRUE www.truedesign.co.uk



@HelpAge



HelpAge International

Copyright © HelpAge International 2018

This work is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License, <https://creativecommons.org/licenses/by-nc/4.0>

Any parts of this publication may be reproduced without permission for non-profit and educational purposes. Please clearly credit HelpAge International and send us a copy or link.

ISBN 978-1-910743-30-0

Introduction

“It’s the most beautiful thing there is, to be able to do what I want because I feel free. A person without independence would be as good as dead.”

Costa Rica, 71-year-old woman

The ability to make our own decisions and go about our daily lives according to our own values and preferences is central to human dignity including when we are older. Everyone has the right to this autonomy and independence.

For many older people, however, the autonomy and independence they enjoyed earlier in their lives is denied in older age – often because others think they can no longer make their own decisions or disregard them when they do. These negative, ageist attitudes towards older people and older age are common, even in societies where there remains a strong rhetoric around respect for older people.

“I am seen as if I am finished. This I will not accept.”

Nigeria, 78-year-old man

The lack of access to care and support services, as well as the lack of choice and control over these, prevents many older people from living independent lives.

“The moment we have to ask someone to do something for us, our independence vanishes as we depend on their will and mood.”

Serbia, 69-year-old woman

This lack of choice and control extends to the final days of life when many older people have no access to palliative care to help them die free from pain and unnecessary suffering. The concept of palliative care is completely new to many older people and services are limited or non-existent in many communities.

“I do not know about such services. Everything falls on the shoulders of relatives.”

Russian Federation, group discussion

This report presents the themes and issues raised by 450 older people from 24 countries in a consultation on their rights to autonomy, independence, long-term care and palliative care (see Annex 1 and 2 for the questions, list of countries and more information on the consultation). In light of the responses, the report makes recommendations on the content of these rights.

The aim of this report is to inform the discussions on the rights of older people at the national level in preparation for the 9th session of the UN Open-ended Working Group on Ageing (OEWG: see Annex 3), at the OEWG session itself in July 2018 and at future OEWG sessions.



Key findings

Awareness of older people's rights to autonomy, independence, long-term care and palliative care is low among older people themselves, their family members and others, such as service providers.

Although there is no significant difference between genders in the responses, some participants said older men had more autonomy and control over family affairs than older women.

Autonomy and independence

- Older people want to lead autonomous and independent lives. Autonomy and independence are highly valued.
- Many older people are not able to make their own decisions about their finances, 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 are preventing, or interfering with, older people's autonomy and independence, including government and local authorities, policy makers, local leaders, service providers and family members.
- A deterioration in health or income, the loss of a job or retirement, and a change in circumstances, such as going to live with a family member, are events that make older people dependent on others, which means they lose autonomy and independence.
- There are no explicit standards on autonomy and independence in older age in international human rights law.

Long-term care and support services

- Many older people have no access to, or choice and control over, the care and support services they may need to live independent lives.
- The types of care and support services available to older people vary in some respects across regions but in every region long-term care and support services are limited and unaffordable to everyone except those with high income.
- Family members are the only care and support providers available to most older people.
- Without care and support services, loss of income and deterioration in health make older people depend on others.
- There is no explicit standard on the right to care and support for independent living in older age in international human rights law.

Palliative care

- Many older people have no access to palliative care to help them die free from pain and unnecessary suffering.
- Palliative care services are limited or non-existent in all countries included in the consultation.
- 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.



1. Autonomy and independence

1.1 Lack of autonomy in older age

The majority of older people who took part in the consultation reported not being able to make their own decisions in one or more different areas of their lives including finance, employment, management and disposal of their property, who to vote for, where and with whom to live, and access to health services.

“I have no control over money and resources.”

Mauritius, 63-year-old woman

“We are forced into retirement and not allowed to work.”

Mongolia, 90-year-old woman

“Nowadays my children and younger villagers don't see my worth any more. They make decisions without me participating. They can decide to sell some of my property without telling me.”

Tanzania, 81-year-old man

“During elections the person who transports you tells you who to vote for.”

Uganda, group discussion

“In health issues we do not have the possibility or the support to choose the type of care we want to have, the type of treatment and appropriate medications.”

Colombia, group discussion

Some older people said they were not able to make their own decisions about their participation in community or voluntary activities. Other participants reported they had no say over their free time and leisure activities. A small minority said they could not make decisions about their own life plans or personal relationships.

“[I can't make my own decisions around] attending recreational events and joining organisations because I need to ask for my children's permission as I am taking care of my grandchildren.”

Philippines, group discussion

“My daughters vow they will never allow me to marry another wife.”

Nigeria, group discussion

In one case, older people reported not being able to choose their religion.

“We cannot decide the church because we live in a Catholic charitable home. We are obliged to be Catholic.”

Rwanda, group discussion

Some participants talked about being excluded from household activities or decision-making processes, such as what household items to buy, being able to have visitors or being able to visit relatives.

“Within the family, there is difference between women and men in old age to control family affairs. Men have more power.”

Myanmar, group discussion

“I look after my grandchildren despite my bad health. I have to, there is no other choice.”

Serbia, woman in her seventies

Some participants talked about having no say over the type of food they eat, the time when they have their meals, the type of clothes they wear or the time when they can use the bathroom.

“I would like to have a say on the type of food I wish to eat.”

Uganda, 74-year-old man

For some participants, the possibility of having more control over their lives was hard to imagine.

“I'd like to but objectively cannot. I am fully dependent on my brothers and sister who do not live with me and have their own families.”

Serbia, man in his seventies

“I would like that, but no one needs me.”

Russian Federation, 65-year-old woman

Some participants said they were able to make decisions in every aspect of their lives.

“Now, at this stage of life, I feel that I can make decisions freely.”

Costa Rica, 81-year-old woman

A smaller number said they were unable to make decisions in any aspect of their life.

“In any aspect of my life I am unable to make my own decisions.”

Nepal, 81-year-old woman

1.2 Denial of older people's autonomy

Older people identified a range of different people as barriers to, or interfering with, their autonomy.

Family members included children (sons, daughters and daughters-in-law), grandchildren, spouses, siblings and other relatives.

“My children want to control my life.”

Nigeria, 78-year-old man

They identified people in positions of authority including traditional leaders, local authorities, policy and lawmakers, and government officials.

“Some of the authorities of the Municipality or Department do not offer support.”

Bolivia, 61-year-old woman

Service providers were also reported as preventing older people from making their own decisions including landlords, managers and staff in residential care facilities, and caregivers. Laws and policies were also identified as barriers to autonomy. These included tenancy laws, rules and policies of residential care facilities, poor regulation of social services, and lack of information and obstructive bureaucracy surrounding access to services.

“The leaders of the home, the caregivers, and the rules and regulations of this institution [are preventing us from making our own decisions].”

Rwanda, group discussion in a residential facility

“The employees of the health system or public servants are imposing; they do not have the attitude of listening to us to know what we want or need. They simply decide for us and give orders.”

Colombia, Group discussion

Participants also said ageism and discrimination against older people, traditions and customs, and negative attitudes of family members stopped them making their own decisions.

“The people around us believe that we are no longer able to make our own decisions.”

Bolivia, 71-year-old man

“They think my words are not important and in everything I am bound by traditions and culture.”

Sudan, group discussion

1.3 Loss of autonomy in older age

Many participants identified the deterioration of their health or financial situation, the loss of their job or having to retire as the events that made them dependent on others. This dependence on others resulted in a loss of autonomy.

“[I was no longer able to make my own decisions] soon after I retired from my teaching job 16 years ago and had to come back to my village. I lost my husband a few years later and my income started declining.”

Tanzania, 76-year-old woman

“I used to have a salary higher than the pension I receive. With such a small pension, I cannot do anything. I need to ask my children for support.”

Moldova, group discussion

“After I had a stroke my body started weakening and I had to stop working. They see me as less than when I was stronger and healthier.”

Philippines, group discussion

Changes in family circumstances were also reported as common factors that can trigger a loss of autonomy. These include the death of a spouse, children growing up or getting married, the birth of grandchildren, giving property to children, going to live with children or other family members, or moving into a residential care facility.

“There is a moment in life in which children take control of the home and forget to include older people.”

Colombia, group discussion

“Since my son has brought me to live in their apartment in the city, I do not have a say anymore. Sometimes I am locked in my room.”

Nigeria, 68-year-old woman

Jeff Williams/HelpAge International (Tanzania)





“My friend was forced to take care of her grandchildren, and at that time she stopped being independent.”

Chile, group discussion

“[The loss of autonomy] started when we became residents of this institution.”

Rwanda, group discussion in a residential facility

For some older people the factor that triggered their loss of autonomy was getting older and the stigma attached to older age.

“The time when things began to change was when I grew older and I started to be seen as a burden to society.”

Sudan, group discussion

“I never had the chance to make my own decisions freely at any stage of life. But I feel that my decisions are becoming more valueless as I grow older.”

Nepal, 71-year-old woman

Autonomy and independence

These terms are often used interchangeably. These suggested definitions show how they are distinct but also interdependent on one another.

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

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

1.4 What independence means to older people

Participants understood independence as making their own decisions as well as doing things for themselves and in their own way.

Most understood independence as the ability to make their own decisions freely and without interference from other people.

“It is the freedom to decide for ourselves.”

Peru, group discussion

“[Independence means] to be able to make my own decisions without fearing the consequences.”

Slovenia, woman in her seventies

“[Independence] is the freedom to do as you wish, not being controlled by anybody.”

Kenya, group discussion

Some participants said having their rights respected and being able to exercise them freely was a core part of their independence. They also said independence was having the freedom to act in different aspects of their lives: freedom to raise their voice and express their opinions; freedom to join associations; freedom to go where they wish; freedom of religion; freedom to choose their personal relationships and how they spend their leisure time; and freedom from fear and abuse.

“[Independence] means that other people cannot decide how I use my property or income, who I socialise with, and where and when I choose to go.”

Serbia, 80-year-old man

“[Independence means] doing what I enjoy doing.”

Myanmar, group discussion

They also talked about financial independence and the importance of having sufficient income, being able to work to support themselves, having control over their finances, and owning and managing their property.

“Independence means having full control over one’s life which mostly relies on one’s financial capacity.”

Zambia, 73-year-old man

“[Independence means] being able to earn a living within one’s means – not always begging or depending on other people for support.”

Tanzania, 81-year-old man

“We have la Renta dignidad [non-contributory pension] but that is not enough, with that we cannot be independent.”

Bolivia, 60-year-old man

Independence was also related to good health. Many participants said they started to lose their independence when their health deteriorated.

“Independence exists as long as we are healthy enough to do the things we need to do unassisted. The moment when we have to ask someone to do something for us, our independence vanishes as we depend on their will and mood.”

Serbia, 69-year-old woman

Central to independence was being able to participate in decision-making, family and cultural life, and to act on their own ideas, do things for themselves, solve their own problems and achieve their goals.

“[I am independent when] nobody hinders my plans or dreams.”

Philippines, group discussion

“Being able to perform activities of daily life independently, with adequate physical and mental health. Even with the support of a caregiver, you are still perceived as an independent person.”

Group discussion, Argentina

Access to services was central to older people’s understanding of independence.

“[Independence] is to have adequate basic services (health, education) and social systems (family, church and so on) adapted and inclusive, that allow people to live the lives they want to live.”

Colombia, group discussion

“I am paralysed if I don’t have access to Wi-Fi and my phone doesn’t work.”

Slovenia, 67-year-old man

1.5 Autonomy and independence in human rights law

There are no explicit standards on autonomy and independence in older age in international human rights law.

Everyone’s right to equal recognition before the law¹ and the right to a family and private life,² which are both central to autonomy and independence, are enshrined in international human rights law. However, there are no explicit international standards on how these rights apply in older age.

Some regional human rights standards recognise the right to autonomy and independence in older age. However, these vary and are inconsistent across regions.

Article 7 of the Inter-American Convention on Protecting the Human Rights of Older Persons (2015) affirms older people’s right “to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights”. Article 11 affirms their right “to express their free and informed consent on health matters”.

Article 5 of the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons in Africa (2016) recognises older people’s right to make decisions.

The right of older people to lead independent lives is recognised in Article 25 of the European Union Charter of Fundamental Rights (2000) and in Article 23 of the European Social Charter (1996). The Council of Europe’s Recommendation CM/Rec(2014)2 on the promotion of the human rights of older persons makes recommendations on older people’s autonomy and participation and their consent to medical care.

To enjoy their right to autonomy and independence older people must be recognised as rights holders under the law and must be able to take action and make decisions that are legally recognised.

Being a rights holder and being able to take action and make decisions that are legally recognised is known as ‘legal capacity’. Everyone has the right to legal capacity, and it is essential for autonomy and independence and for full participation in society. Legal capacity is not the same as cognitive or mental capacity, which refer to decision-making skills and vary from one person to another. An individual’s decision-making skills and ability may fluctuate over time and may vary from one type of decision to another. The Convention on the Rights of Persons with Disabilities establishes that no one can be denied legal capacity because of disability or their decision-making skills.³

Older people, therefore, should never be denied their status as rights holders, the full protection of their rights under the law nor their right to make decisions and take action because of their actual or perceived decision-making skills. They should also never be denied legal capacity because of their actual or perceived age. Instead, older people should have the right to support with making decisions in circumstances where they may need it. For example, dementia or other forms of cognitive impairment may affect older people's decision-making skills in particular aspects of their life.

Support with decision-making can take different forms: for example, having someone you trust to assist you with a decision, having information provided to you in an accessible way or being able to say in advance the type of care or medical treatment you would like in the future. Support with decision-making should never be imposed on an older person, and decisions made should always be based on the older person's will and preferences, or the best interpretation of them.

These rights to autonomy, independence and legal capacity in older age are not clearly articulated in international human rights law and need to be included in a new UN convention on the rights of older people.



Ermishin Oleg/HelpAge International (Ukraine)

1.6 Recommendations on the right to autonomy and independence

These recommendations on what the right to autonomy and independence should look like are informed by older people's experience of autonomy and independence as reported in this consultation.

Older people have the right to 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.

All aspects of life

- The right to autonomy and independence should apply to choice and control in all aspects of older people's lives, including but not limited to making decisions about their support and assistance; leisure time; property; income; finances; place of residence and living arrangements; health and medical treatment or care; end of life care; personal, family and private life, including sexual and intimate relationships; political participation; and funeral and burial arrangements.
- This should include the right to have those decisions respected.

Participation

- The right should include full, effective and meaningful participation in family, social, cultural, economic, public and political life, and educational and training activities.

Living arrangements

- Older people should have the right to live independently in the community on an equal basis with others. This includes the right to choose where and with whom to live, without being obliged to live in any particular living arrangement.
- When older people choose to live in shared residential settings, such as residential care and support facilities, their right to autonomy and independence should also be respected.

Support services

- The right should provide for access to support services. These include support services to make decisions and exercise legal capacity, and services to support independent living and inclusion in the community.
- Support services should be available on an equal basis in home, community and residential settings.
- Older people living in shared residential settings should be provided with specific and tailored support services to exercise their right to autonomy and independence in order to accommodate any cultural, spiritual, professional and environmental challenges of these facilities.

- Community services and facilities that are available to the public should be available to older people on an equal basis and be responsive to their needs.
- Mechanisms designed to enable the exercise of older people's right to autonomy and independence should recognise older people's right to legal capacity on an equal basis with others in all aspects of life.

1.7 Recommendations on the right to equal recognition before the law

These recommendations on what the right to equal recognition before the law should look like are informed by older people's experience of autonomy and independence as reported in this consultation.

Older people have legal capacity at all times and are recognised before the law on an equal basis with others.

Decision-making

- Older people should have the right to designate trusted persons to support them with making decisions based on their own will and preferences where the older person's will and preferences may not be easily understood by others.
- Older people should have the right to set out their will and preferences in advance, in case they may not be in a position to communicate them in future.
- Older people should have the right to participate in, and challenge, any decisions that interfere with the exercise of their legal capacity.

All aspects of life

- The right should apply to all aspects of life.

Support services

- The right should provide for access to the mechanisms and support older people may need to exercise their legal capacity in accordance with their will and preferences, and on an equal basis with others.
- The right should provide for access to appropriate and effective safeguards to prevent abuse in the exercise of older people's legal capacity. These safeguards should respect older people's will and preferences in accordance with international human rights law. They should be free of conflict of interest and undue influence, and should be tailored to the older person's circumstances.

Remedies and redress

- The right should include effective access to justice and redress for older people. This includes the provision of accommodations and special measures to prevent unnecessary delays in the legal process.
- The right should provide an obligation on states to ensure trusted persons, support and other service providers receive appropriate training in this area. This includes but is not limited to notaries and medical personnel, and those working in the administration of justice, such as police and prison staff.

Equal recognition before the law is a basic general principle of human rights protection and is necessary for the enjoyment of all other human rights.

Legal capacity is the capacity to be both a holder of rights and an actor under the law. As a holder of rights, a person is entitled to full protection of their rights by the legal system. As an actor under the law, a person has the power to engage in transactions and create, modify or end legal relationships.⁴

Supported decision-making allows people to maintain their autonomy and independence by choosing different types of support to assist them to make their own decisions and choices.

A trusted person is an individual an older person chooses to ask for advice or other types of support before making decisions. This could be a friend, a family member or someone else the older person trusts.

Amy Heritage/Age International (Mozambique)





2. Long-term care

2.1 Care and support available to older people

A large number of participants said there were no long-term care and support services available in their community other than the support provided by family members

“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 truth is these services are scarce and cannot meet the demand.”

Zambia, 72-year-old man

Although some participants described having access to one or two specific services, such as home-based care, day centres, community support and residential facilities, their responses suggest a lack of access to comprehensive systems of long-term care and support.

“[I have access to] homecare and treatment, but this only covers a tiny proportion of my needs.”

Serbia, man in his seventies

Participants said the types of services provided included support with laundry, housework, hospital visits, shopping, taking medication, electrical and plumbing repairs, gardening, payment of bills, hearing aids and glasses, fitness activities and free food distribution.

“[I have access to] services provided by social workers: payment of bills, purchase of medicines, cleaning, gardening, and coming with me to see the family doctor twice a week.”

Moldova, group discussion

2.2 Care and support providers

Participants identified the family as their main provider of care and support.

“The family is the main caregiver and provider of palliative care. It is a responsibility that the state has almost completely delegated to the family.”

Colombia, group discussion

Other people identified as providers of home-based care and support were friends, domestic workers, paid live-in assistants, social workers and volunteers from NGOs, older people’s associations and churches.

“We have no care or support services for older people in this community except what we get from KARIKA [a community based organisation].”

Kenya, group discussion

Participants said day centres and residential facilities were available in some communities. These were run by the state, the private sector or faith-based organisations.

“If you can afford them, there are well-equipped private places, especially for people suffering from Alzheimer’s who can no longer live alone and do their things.”

Costa Rica, 84-year-old woman

“A lot of [residential care] homes are not recognised by the Ministry of Health which is very dangerous.”

Chile, group discussion

Long-term care is “the activities undertaken by others to ensure that people with a significant on-going loss of intrinsic capacity [physical and mental capacities] can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.” WHO⁵

Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society.⁶

Types of support services

- mobility support, such as assistive technology or service animals
- communication support
- support for daily activities such as eating, dressing, personal hygiene and sanitation, visiting friends, going shopping, participating in leisure activities, and participating in other social, religious, cultural, political or educational activities and personal relationships on an equal basis with others
- support in decision-making, including the possibility of making decisions in advance around budgeting and financial planning, the making of wills, healthcare, and end of life care
- support to ensure decent employment
- services to secure housing and household help
- community services
- support to access and use services available to the general public such as health, education, transport and justice
- support to participate in the design and development of policies and support services to meet their needs
- support to use new technologies

2.3 Barriers to accessing care and support

Most participants described having difficulties accessing care and support services even when these were available. Services were too costly, insufficient or it was difficult to find information about them.

“[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

They said other barriers to access were failing eligibility criteria, bureaucracy, having to travel long distances and a lack of government policy.

“[A barrier to accessing care and support is] bureaucracy. To receive disability benefits you must annually confirm your status as a disabled person. It turns out you need to go to the hospital and get a paper that [confirms] for the year you have not grown a new leg or kidney. It would be funny if it weren’t so humiliating.”

Kyrgyzstan, woman in group discussion

“[A barrier to accessing care and support is] lack of government policy on care or homes for older people.”

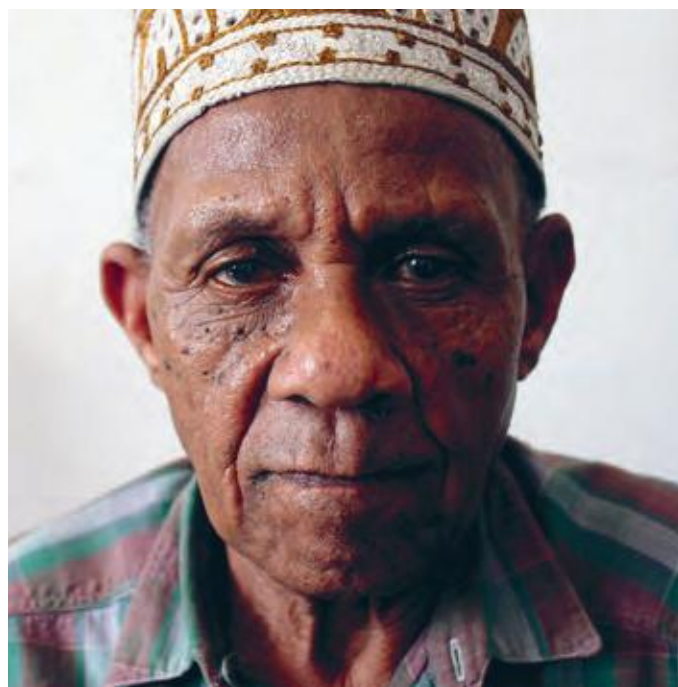
Nigeria, 68-year-old woman

Family members’ shame at being seen as inadequate carers was also identified as a barrier.

“Some people say they cannot leave their parents in a care centre since people will gossip and say they have been defeated in caring for their parents.”

Sudan, group discussion

Judith Escribano/Age International (Tanzania)



Some older people said they would like to move into a residential care facility while others said they would prefer to live in a different place. A number of participants did not trust the quality of the services available in residential care facilities or said attitudes of service providers were hostile.

“People who provide these services have a negative attitude towards older persons so we just avoid them.”

Uganda, 68-year-old woman

Some participants said they would not ask for support from others.

“[A barrier to accessing care and support is] personality factors that hinder the request for help (shame, fear, low self-esteem).”

Argentina, group discussion

2.4 Choice and control over care and support

The majority of participants reported having no say in the management of their care and support.

“We do not have any say since it is a favour.”

Kenya, group discussion

“Usually an old person has to put up with the way they are cared for.”

Russian Federation, 65-year-old woman

“[I have] no say on services provided by the authorities; no say on activities organised by the Community Development Association; no consultation or involvement of older persons in activities organised for older persons at the village council level.”

Mauritius, group discussion

“The truth is current programmes or provisions of the government are unfit and incompatible or inappropriate for the needs of older persons.”

Philippines, group discussion

Some older people reported having full or partial control over their care and support.

“I have a lot of say, but what my relatives can actually do is limited.”

Serbia, man in his seventies

A very small number of participants said that they were able to set out in advance the kind of support they might need in future. The majority said it was not possible to give such instructions in advance, or did not know if was possible.

“With the new law, the user should have a choice on whether to have an informal caregiver (relative) or formal care. There is still a question about financial resources.”

Slovenia, 67-year-old man

“There are no opportunities [to say your support preferences in advance].”

Rwanda, 77-year-old woman

Half of the participants said they had told their care and support preferences to family members, friends, neighbours or local civil society organisations. The other half reported not having shared the information with anyone.

“I am already testing two people helping around the house although there is no pressing need at the moment.”

Serbia, woman in her seventies

“No one ever thinks that something will happen to you and that you will need support. I’ve never talked to anyone. I hope I do not need it.”

Costa Rica, 68-year-old woman

“[I tell] my family, especially my children.”

Zambia, 61-year-old man

“There’s an Older People’s Association representative who brings these needs to our health centre and local authorities.”

Cambodia, group discussion



HelpAge International (Kyrgyzstan)

2.5 Long-term care in human rights law: care and support for independent living

There is no explicit standard on long-term care in older age in international human rights law.

Article 19 of the Convention on the Rights of Persons with Disabilities (2006) establishes the right to independent living for persons with disabilities, which applies to older persons with disabilities and which includes provision of support services to enable such independent living.

There is also a growing body of advisory documents by UN Treaty Bodies and Special Procedures that establish older people's access to support services as a right. This includes recommendations by the Committee on Economic, Social and Cultural Rights in their General Comment No.4; the Committee on the Elimination of Discrimination against Women in their General Recommendation No. 27; and the Independent Expert on the enjoyment of all human rights by older persons in her 2015 thematic report that recommends states should provide care and support services to older people so that they can live independently.

Some regional human rights standards recognise care and support for independent living in older age. However, these vary and are inconsistent across regions.

The Inter-American Convention on Protecting the Human Rights of Older Persons (2015) states in Article 12 that older people have the right to a comprehensive system of care that not only protects and promotes their wellbeing but also maintains their independence and autonomy.

Articles 10 and 11 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa (2016) establishes limited states' obligations in relation to care and support in home and residential settings.

Article 25 of the European Union Charter of Fundamental Rights (2000) recognises older people's right to lead a life of dignity and independence and to participate in social and cultural life. Article 23 of the European Social Charter (1996) establishes older people's right to social protection to enable them to remain full members of society, to choose their lifestyle freely and to lead independent lives. The Council of Europe's Recommendation CM/Rec(2014)2 on the promotion of the human rights of older persons makes recommendations on both home and residential care settings.

These human rights standards can contribute to a better understanding of the role of the state in the on-going discussion about the respective roles of the individual, family and state in relation to long-term care.

Central to these standards is that care and support services should enable older people to live independent and autonomous lives. Likewise, many participants in this consultation expressed their desire for care and support services that would enable them to live their lives

according to what is important to them. Framing older people's right to care and support services in the context of independent living will ensure those services enable older people to lead autonomous and independent lives in any setting they choose to live.

This right to care and support for independent living in older age is not clearly articulated in international human rights law and needs to be included in a new UN convention on the rights of older people.

2.6 Recommendations on the right to care and support for independent living

These recommendations on what the right to care and support for independent living should look like are informed by older people's experience of care and support services as reported in this consultation.

Older people have the right to care and support services for independent living. These should be adapted to their individual needs, promote their well-being and maintain their autonomy and independence, without discrimination of any kind.

All settings

- The right should apply to all settings, public and private, including but not limited to the home, the community and residential settings.
- The right should provide access to a range of care and support services in different settings, including assistive technologies. These should be easily available and affordable, and should ensure older people can enjoy their right to choose where they live and with whom on an equal basis with others.

Person-centred

- Older people's right to care and support services should be independent of and unrelated to their income and the income of their family members.
- Care and support services should be adapted to older people's individual needs and preferences.

Autonomy

- Older people should have the right to access to mechanisms, including supported decision-making processes, which enable them to exercise their right to autonomy and independence in relation to any support services they may require.
- Older people should have the right to make free and informed decisions on all aspects of the care and support services they receive from start to finish and in advance if necessary.
- Older people should have the right to opt out of the care and support service at any time.
- Older people should have the right to control over the planning, delivery and monitoring of their care and support, and they should have access to support with decision-making where necessary.

- Older people should have the right and opportunity to make advance instructions on the type of care and support they would like and who provides it, should it be required at a future point in time.
- Older people can designate one or more trusted persons to assist them to make decisions based on their own instructions, will and preferences where the older person's will and preferences may not be easily understood by others.

Participation

- The right should provide for care and support services to ensure older people have the opportunity to participate in the community and in social, cultural, public and political life, and educational and training activities on an equal basis with others.
- Older people should have the right and opportunity to participate in the design, development and evaluation of care and support services such as, but not limited to, assistive technologies and devices.
- Older people should have the right and opportunity to participate in policy decision-making processes on all forms of care and support, including assistive technologies.

Standards and quality of support

- States should ensure regulation, monitoring and enforcement of accreditation and quality standards of care and support provided by both the state and private enterprises, including not-for-profit organisations or religious bodies. Quality standards should be based on international human rights principles.
- All care and support service providers, including informal or family providers should receive education, training, supervision and support, including respite. Service providers should also be subject to laws, policies and procedures to protect older people from violence, abuse and neglect.

- The state should ensure appropriate resourcing and training of care and support providers and raise public awareness to safeguard the rights of older people using care and support services in any setting.
- Research, design, development and monitoring of care and support services, including assistive technologies, should be carried out in accordance with international ethical research standards.

Remedies and redress

- Older people should have the right to access effective dispute resolution and complaint mechanisms; and administrative and judicial processes to seek redress for violations of their rights.

Information

- The right should provide for older people's access to information about their health status so their decisions can be free, informed and made in advance if necessary.
- The confidentiality of information should be guaranteed.
- Older people should have access to information about care and support services, including assistive technologies, so they can effectively use, select and opt out of services.
- Older people should have access to information and training on the use of assistive technologies, including digital and technical skills, so that they can evaluate the risks and benefits of these services.

Financing

- States should have an obligation to develop and implement policies to address public and private financing of care and support services so they are affordable to everyone who needs them.



3. Palliative care

3.1 Palliative care services available to older people

Many older people said there were no palliative care services in their community, or there were none that they knew about.

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

“There are no hospices for older people in the country.”
Kyrgyzstan, group discussion

The responses suggested that some older people had never heard of palliative care before.

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

“I do not know about such services. Everything falls on the shoulders of relatives.”
Russian Federation, group discussion

Although, some older people said there were one or two palliative care services available to them, such as pain relief, spiritual support, counselling, medication for chronic diseases, massage and support with personal hygiene. However their responses suggested a lack of a comprehensive system.



Kovalenko Konstantin/HelpAge International (Ukraine)

Some participants said services were only available in large cities outside their community. Places providing palliative care services included hospitals and hospices, and some participants received support at home. Services were provided by the state, the private sector or NGOs.

“Where I live, there is a pain clinic.”
Costa Rica, 81-year-old woman

“[There are] religious services and psychosocial support.”
Tanzania, 75-year old man

“There is no service for palliative care in the community, the health centre is at a distance of 10 km and the nurse performs care once a month.”
Bolivia, group discussion

3.2 Barriers to accessing palliative care

Older people identified high costs and lack of information as the two most common barriers for accessing palliative care where these services were available.

“[The main barriers are] no money, distance and the negative attitudes of the workers.”
Uganda, 74-year-old man

“[The main barrier is] the lack of one’s own foresight of not having registered for insurance.”
Peru, group discussion

Other barriers older people reported included insufficient and poor quality services, long distances between home and services, long waiting lists and bureaucracy. Restrictive drug laws were also reported; and one participant said the services were not available where they wanted to die.

“[The main barriers are] lack of government support and public social welfare system on these types of care and services.”
Myanmar, group discussion

“[The main barriers are] procedures - it is usually formalities such as registration that take long.”
Mongolia, group discussion

“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

“Some people want to finish their lives among their family at home.”

Slovenia, 80-year-old woman

Some participants said negative attitudes of doctors and medical staff towards older people stopped them from accessing palliative care services.

“My husband died of cancer. When they knew he was not going to recover, they dismissed him as trash in the hospital. This was a very traumatic experience.”

Chile, group discussion

“It is not an area of interest for health professionals across the country in spite of the high rate of non-communicable diseases among the older people here.”

Nigeria, group discussion

Some customs and attitudes were also identified as barriers to accessing palliative care services.

“As a cultural norm, families like to keep their ageing member at home till the end of life, irrespective of the capability and proper attitude of family members towards providing the needed services for the elder.”

Nepal, 75-year-old woman

“Sometimes it is because of personal resistance to be helped.”

Costa Rica, 68-year-old woman

Palliative care is “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.” WHO⁷



Carolyn Canham/HelpAge International (Philippines)

3.3 Palliative care in human rights law

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.

Both the Committee on Economic, Social and Cultural Rights in General Comment No. 14 and the Committee on the Elimination of Discrimination against Women in General Recommendation No. 27 have asserted that states must ensure access to palliative care as part of the right to health.

The Independent Expert on the enjoyment of all human rights by older persons recommended in her 2015 thematic report that the right to palliative care should be enshrined in the legal framework, and that states should ensure the availability and accessibility of palliative care in public and private settings.

The Special Rapporteur on the right of everyone to enjoy the highest possible standard of physical and mental health stated in his thematic report in 2011 that limiting equal access of all persons to palliative care on the basis of age cannot be considered appropriate and may amount to discrimination on the basis of age. In addition, two Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment stated that denial of pain relief may constitute cruel, inhuman or degrading treatment.⁸

Some regional human rights standards recognise the right to palliative care. However, these vary and are inconsistent across regions.

The Inter-American Convention on Protecting the Human Rights of Older Persons (2015) includes the right to life and dignity in old age, Article 6; the right to give free and informed consent on medical matters, Article 11; the rights of older persons receiving long-term care, Article 12; and, the right to health, Article 19.

Article 11 in the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa (2016) recognises the right of older persons in palliative care to receive adequate care and pain management medication but this is limited to residential care settings.

The Council of Europe's Recommendation CM/Rec(2014)2 on the promotion of the human rights of older persons has a detailed section on necessary measures to realise the right to palliative care.

This right to palliative care is not clearly articulated in international human rights law and needs to be included in a new UN convention on the rights of older people.



3.4 Recommendations on the right to palliative care

These recommendations on what the right to palliative care should look like are informed by older people's experience of palliative care as reported in this consultation.

Older people have the right to palliative care without discrimination of any kind.

Holistic palliative care

- The right should apply to palliative care in all settings and not be limited to pain relief or any particular treatment.
- Palliative care services should provide support for family members and others close to the older person, including bereavement support.
- States should ensure prevention of cruel, inhumane and degrading treatment of older people. This applies when pain and other symptoms are not treated adequately.

Accessibility

- Palliative care services should be affordable, available and accessible for older people.
- Older people should have the right and opportunity to make free and informed decisions on their palliative care and any other health matters for the duration of the service and in advance if necessary. Older people should have access to palliative care in settings that meet their needs, will and preferences, including at home and in residential facilities.

- The right should provide for affordable, available and accessible medicines, including controlled medicines, for the treatment and palliative care of older people.
- States should ensure drug control laws and other national legislation and administrative procedures guarantee the availability and access to essential palliative care medications.

Autonomy

- The right should provide for supported decision-making processes where necessary, while making sure older people retain legal capacity.
- States should establish procedures by which older people may prepare 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, including the place where palliative care is provided.
- Older people should have access to different types of support to exercise legal capacity, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences.

Training

- States should ensure adequate and appropriate training of health personnel in palliative care.

Regulation

- States should ensure regulation of all palliative care providers and monitoring of their compliance with professional obligations and standards.

Annex 1: Consultation questions

Autonomy and independence

1. In which aspects of your life are you unable to make your own decisions about what you do or what happens to you?
2. Who or what is preventing you from making your own decisions?
3. Can you identify the time when things began to change and you were no longer able to make your own decisions?
4. Are there areas of life where you would like to have a greater say or control over what happens?
5. What does independence mean to you?

Long-term care

1. What type of care and support services are available to older people in your community who need assistance with daily activities such as getting around, eating, washing, getting dressed, going out and so on?
2. Who provides these care and support services?
3. What stops people from accessing these types of services if they are available?
4. If you receive support in your daily activities, what say do you have over the type of care you receive and who provides it?
5. Do you know if it is possible in your country to say in advance what type of care and support you would like in the future if you need it?
6. Have you let anyone know what type of care and support you would like in the future if you need it?

Palliative care

1. What types of palliative care services are available to older people in your community who need them?
2. What stops older people from accessing palliative care services if they are available?

Annex 2: Countries the older people who participated came from

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

This consultation included 450 participants from 24 countries. There were 350 women and 100 men. Participants were invited to respond as individuals or as part of group discussions, and their responses have not been weighted in any way. In light of the findings, this report makes recommendations on the normative framework of each of the rights. The participants were self-selecting so their responses cannot be considered to be a representative sample of older people.

We would like to thank the following organisations for their support in conducting this consultation with older people:

AMIA Argentina, Sumaj Punchay Bolivia, HelpAge Cambodia, Fundación Oportunidad Mayor Chile, Lazos Humanos Colombia, AGECO Costa Rica, KARIKA Kenya, HelpAge Kyrgyzstan, MFPWA Mauritius, HelpAge Moldova, Centre for Human Rights and Development Mongolia, HelpAge Myanmar, Ageing Nepal, Ageing Nigeria Foundation, Grupo Vigencia Peru, COSE Philippines, Dobroe Delo Russian Federation, NSINDAGIZA Rwanda, Red Cross of Serbia, ZDUS Slovenia, volunteers in Sudan, HelpAge Tanzania, MOPSEA Tanzania, PADI Tanzania, JB Geriatrics Tanzania, MAPERECE Tanzania, Uganda Reach the Aged Association, SCAZ Zambia.

Annex 3: The Open-ended Working Group on Ageing

The UN General Assembly established the Open-ended Working Group on Ageing in 2010. It was set up to identify gaps in the protection and promotion of older people's rights in the international human rights system and how to address them, including through the feasibility of new human rights instruments, such as a UN convention on the rights of older people.

<https://social.un.org/ageing-working-group/>



Lydia Humphrey/Age International (Nepal)

Endnotes

1. For example the Universal Declaration of Human Rights (UDHR) Article 6; the International Covenant on Civil and Political Rights (ICCPR) Article 16; the Convention on the Rights of Persons with Disabilities (CRPD) Articles 5.1 and 12
2. For example UDHR Article 12; ICCPR Article 17: CRPD Articles 22 and 23
3. CRPD Article 12
4. Committee on the Rights of Person with Disabilities, General comment No. 1 (2014) on Article 12: Equal recognition before the law, CRPD/C/GC/1, paragraph 12
5. WHO, *World Report on Ageing and Health*, 2015, page 229
6. Report of the Special Rapporteur on the rights of persons with disabilities, December 2016, A/HRC/34/58, paragraph 13
7. www.who.int/mediacentre/factsheets/fs402/en/
8. Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, January 2009, A/HRC/10/44, paragraph 72 and Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, February 2013, A/HRC/22/53



U Myo Thame/HelpAge International (Myanmar)

Find out more:

www.helpage.org

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

 @HelpAge  HelpAge International