

GUIDING QUESTIONS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING: Long-term and Palliative Care

National legal framework

1. What are the legal provisions in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?
1. There is no Long-term care policy but there is Palliative care Policy which doesn't address specific needs for older people
2. There are catered for Palliative care but as in general population, the policy has an implementation plan but there is no budget for it, hence not implemented.

Normative elements

2. What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.

Affirmation

1. Older persons should have the right to adequate knowledge and awareness on Palliative Care.

Scope of the right

- 1.1 Older persons have right to understand of what Palliative care is and how it enhances life. Palliative care is only seen as only valuable at the end of life and yet the benefits are vital from the point of diagnosis.
- 1.2 Older persons have the right to know how they can access palliative care services.
- 1.3 Older persons have the right to designate their care givers to get information on the availability of Palliative care services at all levels of health system.
- 1.4 Older persons have the right to participate in the design, development and implementation of Palliative Policy.
- 1.5 Older person should have right to discuss about the future, as this is vital if the patients are to be permitted the dignity of deciding how to spend their remaining time.
- 1.6 Older people have right to disclosure, diagnosis, prognosis, and transition to PC and the holistic care plan.

State obligations

1. State Parties shall take appropriate and effective measures:
 - 1.1 To ensure there is appropriate legal frame-work or mechanism in place for effective and timely dissemination of palliative care Policy.
 - 1.2 To ensure effective access to information so that older persons can access Palliative as early , from time of diagnosis of a life- threatening illness or serious chronic illness to prevent unnecessary delay.
 - 1.3 To ensure appropriate strategies for involvement of older person in the design, development and implementation of Palliative care policy

Affirmation

2. Older people should have the right to quality palliative care services which are accessible, available and affordable.

Scope of the right

2.1 older people should have right to palliative care which is free from discrimination and in a dignified manner.

2.2 Older people have right to health service, health schemes which are not discriminatory based on their age.

2.3 Older people have a right to access palliative care medicine which is crucial to high quality and effective pain and symptom control.

State obligations

2. State Parties shall take appropriate and effective measures:

2.1. Ensure that PC is integrated at all levels of primary health care –

2.2. Strengthen capacity of health care professionals in gerontology, geriatrics and palliative care---

2.3. States are obliged to respect the right to health by refraining from denying or limiting equal access for older people to Palliative care health services -----

2.4. State has binding legal human rights obligations, of which it must absolutely ensure that everyone is free from unnecessary suffering. Ensure access to pain medication-

2.5 State must ensure that adequate preventive, curative, and palliative health care is of sufficient quality to everyone who needs it

2.6 State should be including Palliative health care budget in their planning.

3. How should *long-term care* and *palliative care* be legally defined?

The legal term of long –term care and Palliative care should be defined as follow: “Palliative Care does not mean you are immediately dying, rather it is when treatment will no longer fully heal or cure your life threatening illness. It is about living well (holistic care) and your family with the life threatening illness as well as dying in dignity

Implementation

4. What are the policies and programmes adopted by your country to guarantee older person’s enjoyment of their right to long-term and palliative care?

- The national policy on the rights of older people is under development by the Ministry of Local Government and social protection, in which the long-term and palliative care is included. Some aspects of long term care is also included in the general population’s social protection policy.
- HSSP IV = Healthy ageing and palliative care-there is a gap in implementation and knowledge sharing.

“Though we, older people are most at risk to NCDs, there is no specific service for us, we have no idea of what is palliative/elderly care, health services are not elderly friendly, we are always told

by health professionals that our problems are related to our age, as if we cannot feel sick like other people". Older people in the City of Kigali, in the consultative meeting held on January 12, 2019

5. What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

Best practices. Ideally there should be the following:

- Need assessment
- Consultative meetings with different stakeholders
- Policy brief
- Policy development
- Adoption of the laws on long-term and palliative care
- Older persons council

Challenges due to lack of:

- Inadequate resources especially in budget allocation and human resource capacity (number and technical capacity)
- Ratification of the Protocol to the African Charter on Human and People's Rights on the Rights of Older Persons in Africa
- Lack of an adopted and approved legal and policy framework on older persons and inclusion of long term Care and palliative care in constitution and relevant laws and policy frameworks
- Lack of a multisectoral coordination mechanism to coordinate ageing and older people issues at national and subnational levels.
- Strategic and operation/implementation plans
- Lack of collection and analysis of disaggregated data in both regular and administrative data management systems

Equality and non-discrimination

6. Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situation?

Participation

7. Does the design and implementation of normative and political framework related to long-term and palliative care include an effective and meaningful participation of older persons?

NO, older people were not consulted/involved in the design of palliative care

Accountability

8. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to long-term and palliative care?

There is no way for older people to complain for denial of the right to long-term and palliative care.