

**THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED
WORKING GROUP ON AGEING:**

International Association of Homes and Services for the Ageing (IAHSA)

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Long-term and Palliative Care

National legal framework

1. What are the legal provision in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?

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.

Long-term care

- People should be able to access long-term care, services and supports.
- Long-term care should be person centered and affordable.
- Long-term care should promote choice and flexibility.
- A stable, culturally sensitive workforce that is well educated and trained to care for older adults is needed to provide formal long-term care.
- Reliable and valid data is needed to monitor and evaluate affordability, accessibility and quality of services.
- Older adults have a right to be free of inappropriate restrictive practices and free of abuse and neglect.
- People should be able to choose their care and access whatever the services are needed.

Palliative care (from the Clinical Practice Guidelines for Quality Palliative Care, 4th edition)

- People with a serious illness would be able to access palliative care in the community or long-term care setting in addition to the hospital, at any stage of a serious illness.
- Palliative care should be provided at the same time as curative or life-prolonging treatment.
- People would receive palliative care based on their needs and not a prognosis.
- Palliative care should focus on what is most important to the individual or family, setting goals and determining how to achieve them.
- An interdisciplinary team should provide palliative care.
- Palliative care should include physical, psychological, social, spiritual and cultural aspects of care.
- People should be able to choose their care and access the services needed.

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

Long-term care is “an array of healthcare, personal care and social services designed to meet a person's needs

during a short or long period of time to address chronic conditions and/or functional limitations”. Informal, unpaid caregivers provide most long-term care, but it can also be provided in other settings as well. Long term care is generally distinguished from acute and primary care both by its duration and its greater emphasis on personal care and social services.

Palliative care is the medical subspecialty focused on providing relief from the symptoms and stress of serious illness. The goal is to improve quality of life for both the patient and the family. It is beneficial at any stage of a serious illness. Palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

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?

IAHSA encompasses over 50 countries, each of which has unique programs and policies. That said, our ultimate goal should be to a world where we have the programs, resources and services that will enable all of us, regardless of our age, our physical, emotional, cognitive condition, regardless of our socioeconomic circumstances, to have those options, choices and the ability to select how we want to age with quality of life, irrespective of ability or disability.

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

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?

Older adults should participate in solutions to resolve access to care issues. They have years of wisdom and often are able to develop workable programs that would benefit everyone.

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?