

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

**FOCUS AREA: LONG-TERM AND PALLIATIVE CARE**

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**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?**

Right now India is at a stage where we are recognising that palliative care is a basic human right. India's Supreme Court has repeatedly affirmed that right to life and personal dignity subsumes the right to die with 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? Article 41 of the Constitution directing the State to ensure the wellbeing of the elderly, the Maintenance and Welfare of Parents and Senior Citizens Act, 2007, and the National Policy on Older Persons, 1999, and the National Programme for Healthcare of Elderly, 2011, and the National Programme for Palliative Care, 2012, offer constitutional, legislative and executive framework for implementing the right to long-term and palliative care. States like Kerala are pushing ahead. In 2014, the Kerala Human Rights Commission reiterated a 1984 palliative care policy order that "every district must have a tertiary level pain and palliative care service with a trained doctor and staff nurse housed either in a medical college or in a district hospital".

**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.**

A. It must have a holistic approach and must go beyond just administering medicines and alleviating pain to improving the quality of life of patients and their families.

B. An effective palliative care network requires the involvement of government at

national and state level to provide necessary funds and local government and community to executive and oversee the network.

C. Setting up of training networks for palliative care personnel and families to ensure no patient is left out.

D. Palliative care must be affordable, accessible and instantly available.

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

Palliative and long-term care are approaches to help patients and their families struggling with life-threatening illness secure a holistic treatment of pain and associated physical, psychosocial and spiritual problems through the intervention of doctors and nursing personnel in settings like hospitals, community centres, old age homes or family homes that respect the needs of patients and families while placing a minimum financial burden on families.

## **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 Programme for Palliative Care is a centrally sponsored scheme in which Union and state government splits the cost burden on a 60:40 basis. It seeks to improve the capacity to provide palliative care service delivery within government health programmes such as the National Program for Prevention and Control of Cancer, Cardiovascular Disease, Diabetes, and Stroke; National Program for Health Care of the Elderly; the National AIDS Control Program; and the National Health Mission.

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

Involving governments and the political, bureaucratic and legal fraternity is critical to implementing these rights in a country like India. There are several rights based legislations but implementation is rife with leakages. Sustaining the interest of the government is critical. Generating public pressure is essential. A participatory approach involving private sector is critical in countries like India which rely heavily on private

health care. Tying funds to norms is also important because without adequate capital prevents the meaningful exercise of 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?**

In India, the National Programme for Palliative Care does not have its own funds but are linked to other schemes including the National Program for Health Care of the Elderly which is setting up a network of 18 regional geriatric centres, training of health personnel in geriatric health-care, post-graduate courses in geriatric medicine, district geriatric units with dedicated geriatric OPD and 10-bedded geriatric ward in 80-100 District Hospitals. It is important that government sponsored health insurance schemes offer universal coverage to the elderly. The government health system must take initiative of palliative care centres in a 5 kilometre radius around a public hospital facility.

### **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?**

In countries like India, a significant number of politicians are senior citizens. This does not signify that they will automatically represent the elderly. A participatory approach to legislation and implementation followed up with social audits and a robust public grievance redress system is the need of the hour. Despite requirement for palliative care centre at all district and medical college hospitals these are rarely followed.

### **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?**

India has a law called Maintenance and Welfare of Parents and Senior Citizens Act, 2007, which mandates a maintenance tribunal in every district. All issues related to elderly are covered by the tribunal. The Act also empowers local police to keep tabs on senior

citizens in their precincts. The civil administration is also dutybound to act on receiving requests for maintenance from senior citizens. However, there is a need for more detailed laws that specifically cite palliative care so that the bureaucracy understands their responsibility