

Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing:

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Long-term care and Palliative care

- 1) In your country/region, how is the right to autonomy and independence of older persons defined in legal and policy frameworks?

Long-term care for older persons in India has always been a family affair. The National Policy on Older Persons, 1999, directs the state to improve the quality of life of its citizens. In 2011, Indian Government launched the National Programme for Health Care of the Elderly (NPHCE) to provide additional human resources and funding for home care, screening for early diagnosis, vaccinations for high-risk groups and health education for caregivers. NPCE envisions regional geriatric centers in eight regional medical institutions with a dedicated geriatric out-patient department and 30-bedded geriatric ward for management of specific diseases of the elderly, training of health personnel in geriatric health-care and conducting research. Other projects include post-graduate courses in geriatric medicine, district geriatric units with dedicated geriatric OPD and 10-bedded geriatric ward in 80-100 District Hospitals.

- 2) What are the specific challenges faced by older persons in accessing long-term care?

The elderly population accesses care predominantly through the general healthcare system, which often have limited dedicated service offerings or

facilities for the elderly. The issues of the public health system, such as lack of infrastructure, limited manpower, poor quality of care, overcrowding of facilities, etc., make worse for geriatrics due to insufficient focus on elderly care. For example, India has 7 physicians and 17.1 nurses per 10,000 people, vis-à-vis a global physician and nurse density of 14.1 and 29.2, respectively. In the private health space, provision of medical care for the elderly predominantly takes place through tertiary care hospitals. Most of these hospitals do not have dedicated geriatric care specialists or departments.

3) What measures are necessary to ensure high-quality and sustainable long-term care systems for older persons?

India has begun focusing on non-communicable diseases (NCD) in some districts and elderly are getting screened for diabetes and hypertension regularly and getting medications free of cost. NCD clinics are equipped with staff to counsel on healthy diet and exercise. Health ministry must take initiative through providing mobile geriatric care units. Kerala Government has set up several palliative care units which has mobile services. However, at the national level, it is an unmet need.

4) What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

India has the third largest community of persons suffering from dementia in the world at about 45 lakh people. There is a need for a national dementia policy with very clear and well defined action plan for India. To enjoy the right of long term care, Geriatric Clinics in all medical colleges and in district hospitals are to be set up. The geriatric clinic shall have a team of experts to conduct awareness talks, immunization clinic, dementia clinic and helpline for older people in the region. The service cost is to be less and all services to be under one roof.

5) In your country/region, how is palliative care defined in legal and policy frameworks?

The Indian Association of Palliative Care [IAPC] was formed in 1994 in consultation with WHO and Indian Government. The Association defines palliative care as “the active total care applicable from the time of diagnosis, aimed at improving the quality of life of patients and their families facing serious life-limiting illness, through the prevention and relief of suffering from pain and other physical symptoms as well as psychological, social, and spiritual distress through socially acceptable and affordable interventions”. IAPC activities are aimed at the care of people with life limiting illness such as Cancer, AIDS and end-stage chronic medical diseases including access to pain relief, palliative care capacity building and advocacy.

6) What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

The challenges elderly face include physical pain, depression, a variety of intense emotions, loss of dignity, hopelessness, and even mundane tasks become difficult to fulfill. In India, currently there are 908 palliative care services delivering palliative care through either through home care, outpatient basis and in patient service. More than 841 of these centres are in Kerala. For the vast majority of Indians there is extremely limited access to quality palliative care services. Among the studies done in India, “End of Life Care Policy for the Dying: Consensus Position Statement of Indian Association of Palliative Care” by Stanley C Macaden et.al have recommended making access to palliative care and end of life care as human rights. Himanshu Sharma et.al in their paper on “End-of-life care: Indian perspective” studied the core issues of developing palliative care in Indian setting keeping in mind the ethical, spiritual and legal issues. The Directorate General of Health Services has submitted a report on “Strategies for Palliative Care in India” to the Ministry of Health & Family Welfare in

November 2012. UNFPA India released “Caring for our elders: Early Responses India Ageing Report 2017” in June 2017

7) To what extent is palliative care available to all older persons on a non-discriminatory basis?

Two Centres of Excellence in the country have been recognised as WHO Collaborating Centres. Thiruvananthapuram [Kerala] has WHO Collaborating Centre for Training and Policy on Access to Pain Relief and Calicut [Kerala] has the WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care. The facilities and faculty in these centres and those run by NGOs provide guidance and support on non-discriminatory basis. The coverage of services in terms of availability, accessibility and affordability of palliative care are grossly inadequate. It is estimated that: only 1% of patients that need palliative care receive it; the majority of all palliative care services in the country are available in one state; Kerala. There are few states in the country without a single centre for Palliative care service provision.

8) How is palliative care provided, in relation to long-term care as described above and other support services for older persons?

Palliative care poses an enormous challenge in India. It came here as care of people with advanced incurable cancer. In terms of number of people with advanced incurable cancer, there are probably 10 lakh to 15 lakh patients who die each year and who need access to palliative care, but maybe only 2 or 3 per cent of them get it. If palliative care is expanded beyond end-stage cancer to those with advanced incurable heart or kidney disease or neurological conditions, the potential number of patients who benefit doubles. In Kerala, because of the visionary approach of advocates of palliative care, it is being extended to groups such as paraplegics who after discharge would normally go home and languish there with bed sores and infections and ultimately die. Most cancer patients, having been through multiple rounds of chemotherapy and radiotherapy treatments, are in extreme pain till they die.

9) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

A number of trusts are involved in palliative care but most volunteers and few nurses are undertrained for elderly care. So formal training is essential. Long term care should be priority for government. The NPHCE should include a special infrastructure to deliver and monitor LTC. Systematic development of an exclusive funding structure that is proportionate with the growing older population becomes essential. It should include effective and active coordination and integration of multi-ministerial teams to carry out the policies and programmes for older persons as an urgent priority. Many countries have addressed long-term care within universal health care systems, whether tax-funded or through social insurance.