Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing: Long-term care and palliative care

1. **In your country/region, how is long-term care for older persons defined and provided for in legal and policy frameworks? What types of support and services are covered?**

1.1 The South African legal Framework lacks a specific definition of long term care. It does however define ''care'' which means the provision of physical, psychological, social or material assistance to an older person and includes services aimed at promoting the quality of life and general well-being of an older person.[1]

1.2 There are several types of services available for older persons in South Africa as stipulated in the Older Persons Act (No. 13 of 2006; OPA). This includes the following:

- Community-based care and support services: these services are development, care and support services provided within a community, aimed at promoting and maintaining the independent functioning of older persons in a community, and include home-based care for frail older persons within the community;[2] This service includes (a) provision of hygienic and physical care of older persons; (b) provision of professional and lay support for the care of older persons within the home; (c) rehabilitation programmes that include provision of assisted devices; (d) provision of respite care; (e) Information, education and counselling for family members; (f) caregivers and the community regarding ageing and associated conditions; and (g) provision of free health care to frail older persons.[3]
- Day care: a service within a residential home or a community-based facility which provides social, recreational and health related activities in a protective setting to individuals who cannot be left alone during the day, due to health care and other social needs;[4]
- home-based care: the provision of health and personal care services rendered by formal and informal care givers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death;[5]

[1] Department of Social Development 'South African Policy for Older Persons' (2005)
[2] Ibid p.6
[3] Older Persons Act 13 of 2006
[4] Department of Social Development 'South African Policy for Older Persons' (2005) p.6
[5] Ibid p.7

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

2.1 One of the major problems confronting the Commission is the absence of systematic reliable data on the needs of older persons in South Africa. This presents a major limitation to understanding problems and formulating interventions specifically for older people.

2.2 Inadequate housing conditions are particularly problematic for older people who are impaired, handicapped or disabled. The unnecessary admission of older dependent people in homes for senior citizens has been attributed to the lack of adequate housing.[6]

2.3 Statistics South Africa, in their report on the 'Social profile of vulnerable groups in South Africa, 2002–2011'[7], assessed the situation of the elderly in relation to access to housing and found that 4.3 per cent of elderly-headed households and 3.3 per cent of the elderly resided in informal dwellings. StatsSA further noted numerous adversities that persons residing in informal settlements are subjected to, such as that they are less likely to have access to basic services such as water and sanitation and / or that they are more likely to reside on the periphery of established townships, and far from social amenities. Some older persons in these areas may opt to relocate to an assisted living facility, but typically worry about leaving grandchildren behind in a disorganised household.

3. What measures have been taken/are necessary to ensure high-quality and sustainable long-term care systems for older persons, including for example:

- **Sufficient availability, accessibility and affordability of services on a nondiscriminatory basis?**
- **High quality of services provided?**
- **Autonomy and free, prior and informed consent of older persons in relation to their**
- **long-term care and support?**

[6] Ramashala M 'Living Arrangements, Poverty and the Health of Older Persons in Africa' Population Bulletin of the United Nations. (2001)Un ibid p.15

[7] See: http://www.statssa.gov.za/publications/Report-03-19-00/Report-03-19-002002.pdf

- **Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?**
- **Sustainable financing of long-term care and support services?**

3.1 There are also elder persons who may require modifications and accommodations to be made to the homes or facilities in which they reside. In light of this, the DHS developed the draft *Special Housing Needs Policy and Programme* in June 2015, which would provide capital funding for special need housing projects and ensure the ongoing training of staff and maintenance of facilities. Special Needs housing refers to any form of housing for individuals, who due to their specific vulnerabilities, require adjustments to their housing or who are unable to live independently and require care in state funded or state assisted housing. It refers to housing provided for individuals who due to various vulnerabilities and / or special needs have limited or no capacity to fulfil their rights of access to housing. To date, the Policy has not been approved by cabinet and therefore is not yet in the implementation phase. The Commission is currently in negotiations with the Department of Human Settlements to ensure that this policy is adopted in the near future.

3.2 The Commission recently met with the Parliamentary Committee on Human Settlements in order to raise its concerns with regards to the Special needs policy. The concerns raised included the lack of provision for capital funding that can be used to build institutions that would address special needs. For the most part, Special needs housing is provided by the non-profit (NPOs) and NGO sectors, while selected state departments provide funding to run the homes. NPOs lack adequate state assistance and funding, particularly for capital costs to build new facilities or to renovate existing facilities. Organisations that provide services relating to Special needs housing mainly access funding from the DSD.

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?

4.1 Older persons are entitled to the rights enshrined in the Bill of Rights in the Constitution of the Republic of South Africa (1996). Such rights include (a) Section 9, which prohibits unfair discrimination on the basis of, inter alia, age, (b) the right to dignity contained in Section 10, and

(c) the right to freedom from violence contained in Section 12. The rights enshrined in the Constitution and Bill of Rights supplement the rights that older persons have in terms of the OPA.

4.2 The OPA, which takes a rights-based approach, states that older persons may not be unfairly denied the right to: a) participate in community life in any position appropriate to his or her interests and b) capabilities; c) participate in inter-generational programmes; d) establish and participate in structures and associations for older persons; e) participate in activities that enhance his or her income-generating capacity; f) live in an environment catering for his or her changing capacities; and g) access opportunities that promote his or her optimal level of social, physical, mental and emotional well-being.[8]

4.3 South African Older Persons Charter echoes the rights of all older persons to equality, respect and freedom, as outlined in the Constitution. The Charter also speaks to the rights of older persons living in the community to basic services (shelter, healthcare, water and electricity), social security, as well as affordable and accessible transport, wheelchair access, and the right to receive home-based care. It also encourages the rights of older persons to participate in community life as active citizens.

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

5.1 The National Policy Framework and Strategy on Cancer Defines palliative care as care that "meets the needs of all patients requiring relief from symptoms or pain, and the needs of patients and their families for psychological and supportive care. This is particularly true when patients are in advanced stages and have a very low chance of being cured, or when facing the final or terminal phase of the disease. [9]

5.2 In terms of this policy, survivorship and palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual. Palliative care includes support of the family in caring for the patient at home and bereavement care. There is

[8] Older Persons Act 13 of 2006
[9] Department of Health 'National Framework and Strategy for Cancer 2016-2021' (2015)

much research supporting prolongation of quality of life when palliative care is provided in conjunction with oncology treatment[10]

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

6.1 There is a dire need to increased training and up skilling of health care providers in South Africa. The Palliative care Institute has noted that an estimated 302 000 Health care providers in South Africa still need training on palliative care.[11]

6.2 A study conducted with 1 443 hospital inpatients in the Cape Town Metropole found that 16.6% were found to have an active life-limiting disease with the leading diagnoses being cancer in 50.8%, organ failure in 32.5%, and HIV/tuberculosis in 9.6%. The greatest burden of disease was in the general medical wards, to which an overall 54.8% of patients meeting the requirements for palliative care were admitted.[12]

6.3 In South Africa, poor people, and particularly those living in rural areas, frequently have the least access to quality healthcare, including rehabilitation services. Poor health outcomes have a regressive effect, both increasing the incidence and complexity of healthcare needs in the affected person, and creating additional barriers to accessing healthcare, such as an inability to use public transport or a need for personal assistance when seeking healthcare.[13]

6.4 It is estimated that the vast majority of HIV positive patients (96%) and more than 70% of cancer patients in South Africa experience moderate to severe pain during the course of their disease, because they do not have access to affordable and effective pain medication.[14]

[10] Department of Health 'National Framework and Strategy for Cancer 2016-2021' (2015)
[11] Green B 'Palliative Care Institute' (2016). See https://www.hpca.co.za/item/palliative-care-institute-pci.html
[12] van Niekerk L & Raubenheimer P J ' A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town, South Africa' (2014) South African Medical Journal. See: http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S0256-95742014000200025
[13] Department of Health 'National Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 (2015)
[14] Stassen, W 'Destined to live and die in pain'. The South African Health News Service, (2012).

6.5 Assisted dying remains illegal and prosecutable in South Africa. This position was reinforced in December 2016 when the Supreme Court of Appeal (SCA) handed down a judgment in an appeal brought by the state against a High Court judgment dealing with the question of assisted dying. The case was brought by the terminally ill Robin Stransham-Ford, who had approached the High Court to request the legal sanction for a medical practitioner to end his life, or to enable him to end his life. On 30 April 2015, the Pretoria High Court granted him an order that would allow a doctor to assist him in dying without the threat of prosecution. Unfortunately, Stransham-Ford passed away just hours before the order was made.

6.6 In his judgment Fabricius J made it clear that the relief ordered was case dependent and did not set a precedent that could be open to abuse. According to him, while the right to life is paramount and life is sacrosanct, with section 11 of the Constitution providing for this, 'this provision safeguards a person's right vis-à-vis the State and society' however cannot mean 'that an individual is obliged to live, no matter what the quality of his life is.'

6.7 In 2016 the Minister of Justice and Correctional Services, Minister of Health and the Health Professions Council of South Africa (HPCSA) appealed the High Court judgment, arguing that it would have potential far-reaching implications in the absence of a legislative framework that regulates assisted dying. However the SCA found that Stransham-Ford's cause of action ceased to exist when he passed away, and that more generally the circumstances of the case were such that it was inappropriate for the High Court to engage in a reconsideration of the common law in relation to the crimes of murder and culpable homicide.

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

7.1 Any person, of any age, who has a life-limiting condition, qualifies for palliative care. This includes many different types of illnesses, and is provided for patients as well as their families.

7.2 Older persons are entitled to the rights enshrined in the Bill of Rights in the Constitution of the Republic of South Africa (1996) and in the Promotion of Equality and Prevention of Unfair

Discrimination Act. Such rights include (a) Section 9 of the Constitution, which prohibits unfair discrimination on the basis of, inter alia, age.

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

8.1 In South Africa, due to the focus on primary care, morphine and codeine have been declared essential drugs in primary care settings; a national standard for pain control is also in place, although access is inequitable because of large rural populations and a divided private and public health system.[15]

8.2 However, a South African model of palliative care has been described that covers patients with HIV/AIDS and patients with cancer, whether public or private, which thereby reduces inequity of access. This novel public—private partnership model of palliative-care provision runs from a ward within a district hospital, is entirely funded by the hospital, and works in partnership with the hospice that provides training and input to patient management. The service has been successfully sustained since its creation in 2006.[16]

[15] Harding R; Selman L; Powell R; Namisango E; Downing J; Merriman A; Ali Z; Gikaara N; Gwyther L; Higginson I 'Research into palliative care in sub-Saharan Africa' (2013)
[16] Ibid.