

**Joint submission by AGE Platform Europe, HelpAge International, The Law in the Service of the Elderly and the National Association of Community Legal Centres Australia  
Open-Ended Working Group On Ageing, 9<sup>th</sup> Working Session, 23-26 July 2018**

**Long-term care and palliative care**

**Authors**

1. This joint submission is authored by Robin Allen (Cloisters), Andrew Byrnes (Australian Human Rights Institute, Faculty of Law, University of New South Wales), Israel (Issi) Doron (University of Haifa), Nena Georgantzi (AGE Platform Europe / National University of Ireland Galway), Bill Mitchell (National Association of Community Legal Centres, Australia) and Bridget Sleaf (HelpAge International). Our views do not necessarily reflect the broad and consensual positions of the organisations we represent, which will be submitted separately.

**Context of Response**

2. This response addresses the guiding questions from a global perspective. It is an executive summary of a more comprehensive statement which will be provided to the 9<sup>th</sup> Working Session.

**Guiding Question 1: Long-term care**

3. Living independently at any stage of life means the provision of all necessary support to enable one to make decisions, perform actions of daily living and participate in society in accordance with one's will and preferences.
4. Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society. Knowledge about, access to and choice and control over the support necessary to be able to live according to one's will and preferences is central to autonomy, dignity, and independence in older age.
5. There is no specific right to support for independent living in older age in international human rights law. A wide range of general provisions in international human rights law are pertinent in long-term care settings but their specific application in this area has yet to be fully explored. Article 19 of the Convention on the Rights of Persons with Disabilities 2006, which explicitly guarantees the right to independent living for persons with disabilities and includes provision of support services to enable such independent living, applies only to older persons with disabilities.
6. Some regional human rights standards recognise care and support for independent living in older age. However, these vary and are inconsistent across regions.

**Guiding Question 2**

7. Older persons' choice and control over the support they require is often limited or denied within current systems of long-term care. Support options available may serve the system rather than the individual user's needs and preferences. Support is also often unavailable and may not be guaranteed under the law. Some types of support, for example, personal assistance schemes, may be subject to upper age limits and therefore not available to older persons. Support may also be unaffordable or tied to particular living arrangements.
8. The use of restrictive practices to manage behaviour in long-term care and support settings, including within in-home care settings, is a particular concern. Common forms of restrictive practice in long term care include: detention (e.g. locking a person in a room or ward indefinitely); seclusion (e.g. locking a person in a room or ward for a limited period of time); physical restraint (e.g. claspings a person's hands or feet or mis-use of equipment to stop them from moving); mechanical restraint (e.g. tying a person to a chair or bed); and chemical restraint (e.g. giving a person sedatives or other unnecessary medication to restrict or subdue behaviour). These practices amount to violations of human rights.
9. Isolation, social exclusion, segregation and loneliness can affect older persons regardless of their particular living arrangements.

**Guiding Question 3**

10. Explicit, legally binding international human rights standards are needed on older persons' right to affordable, appropriate, integrated, quality, timely, holistic, care and support services which are adapted to their individual needs, promote and protect their well-being and maintain their autonomy, dignity, and independence, without discrimination of any kind.
11. The right should extend to the provision of care and support services in all settings, public and private, including but not limited to in the home, in the community, and in residential settings.
12. Older persons should have the right to the care and support services they require independent of and unrelated to the income of their family members.
13. States should take steps to ensure, inter alia, older persons:
  - Enjoy autonomy and independence in the exercise of this right

- Are able to participate fully in the community and society
- Have access to effective complaints and redress mechanisms
- Have access to information about their health status and care and support services

14. States should ensure that standards, professionalism, and quality of care and support services are in line with human rights principles.

15. States should ensure that older persons are not denied necessary and appropriate care and support services based on their and/or their family's financial means. States should develop and implement policies to address public and private financing of care and support services.

16. States should ensure effective compliance mechanisms for complaints arising out of a range of issues including pricing, quality, and the protection of human rights in care and support.

#### **Guiding Question 5: Palliative care**

17. Palliative care is an approach that seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering. It also addresses the psychosocial, legal and spiritual aspects associated with life-threatening illnesses and end-of-life care.

18. While existing international human rights treaties do not specify a right to palliative care, there is a growing body of authoritative interpretations and "soft law" that establishes this right. Access to palliative care is both a component of the right to the highest attainable standard of health and implicates the right to freedom from torture, cruel, inhuman and degrading treatment.

19. Some regional human rights standards recognise the right to palliative care. However, these vary and are inconsistent across regions.

20. International human rights standards are needed on older persons' right to quality palliative care services that are available, accessible, and acceptable without discrimination of any kind.

21. The right should apply to holistic palliative care in all settings and should not be limited to pain relief or any particular treatment or setting.

22. States should take steps to ensure, inter alia:

- Quality palliative care services are available, accessible and acceptable for older persons in a setting consistent with their needs, will and preferences, including at home and in long-term care settings
- Availability and accessibility of essential medicines, including internationally controlled essential medicines, for the treatment of moderate to severe pain, and for palliative care of older persons
- A range of supports to exercise legal capacity, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences, and the opportunity to make advanced directives, living wills and other legally binding documents that set out their will and preferences around medical interventions, palliative care and other support and care at the end of life
- Older persons are able to express their free, prior and informed consent to their palliative care treatment and any other health matters
- Regulation and monitoring of compliance of all palliative care providers with professional obligations and standards.