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**HelpAge International submission on the normative elements of the rights of older persons to care and support (long term care) and to palliative care**

10th Working Session of the Open-ended Working Group on Ageing, 2019

**Question 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.**

**1. Normative elements of the right of older persons to care and support for dignified, autonomous and independent lives**

1. Older persons have the right to care and support for dignified, autonomous and independent lives.

1.1 Older persons have the right to affordable, accessible, appropriate, integrated, quality, timely, holistic, care and support services which are adapted to their individual needs, promote and protect their well-being, maintain their dignity, autonomy and independence and enable them to fully participate in society, without discrimination of any kind.

1.2 Older persons have the right to 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.

1.3 Older persons have the right to information about all aspects of their care and support needs and services.

1.4 Older persons have the right to choice and control over their care and support services, and to support to exercise this right.

1.5 Older persons have the right to the care and support services they require, independent of, and unrelated to, the income of their family members.

1.6 Older persons have the right to safeguards to enable them to exercise their right to care and support.

**Autonomy**

2. States Parties shall take effective and appropriate measures

2.1 To make available and accessible to older persons an affordable range of care and support services, including assistive technologies, in different settings to ensure older persons’ enjoyment of the right to choose where they live and with whom on an equal basis with others.

2.2 To ensure older persons have choice and control over care and support services which are adapted to their individual needs and preferences.

2.3 To ensure older persons have access to mechanisms, including supported-decision making, which enable them to exercise their right to autonomy and independence.

2.4 To ensure all aspects of an older person’s care and support, including initiation and termination of services, are carried out with the free, prior and informed consent of the individual. Consent must be on-going, not just obtained at the point of admission and/or commencement of the support service.

2.5 To ensure older persons have control over the planning, delivery and monitoring of their care and support, including access to support with decision-making where necessary, and can opt out of the care and support service at any time.

2.6 To ensure older persons have the opportunity to make legally binding documents on the type of care and support they would like and who provides it, should it be required at a future point in time.

2.7 To ensure older persons have the right to designate one or more trusted persons to assist them to make decisions based on their instructions, will and preferences in circumstances where the older person’s will and preferences may not be easily understood by others.

**Participation**

3. States Parties shall take effective and appropriate measures

3.1 To ensure older persons have the opportunity and are supported to participate in the community and in social, cultural, public and political life and educational and

training activities on an equal basis with others.

3.2 To ensure community services and facilities for the general population are available to older persons on an equal basis and are responsive to their needs.

3.3 To ensure older persons have the opportunity to participate in the design, development and evaluation of assistive technologies and devices.

3.4 To ensure older persons have the opportunity to participate in policy decision-making process on all forms of care and support, including assistive technologies.

**Standards and quality of support**

4.States Parties shall take effective and appropriate measures

4.1 To ensure research, design, development and monitoring of care and support services, including assistive technologies, is carried out with the involvement of older people themselves and in accordance with international ethical research standards.

4.2 To ensure quality standards for care and support services are based on human rights principles.

4.3 To regulate, monitor and enforce accreditation and quality standards of care and support provided in all settings by both state actors and by private enterprises, including not-for-profit organisations or religious bodies.

4.4 To ensure all care and support service providers, including informal or family providers, receive education, training, supervision and support, including respite, and are subject to laws, policies and procedures to protect older persons from violence, abuse and neglect.

4.5 To ensure appropriate resourcing and training of care and support service providers and public awareness to safeguard the rights of older persons receiving care and support in any setting.

**Information**

5. States Parties shall take effective and appropriate measures

5.1 To ensure older persons have access to information about their health status so their decisions can be free, prior and informed.

5.2 To ensure the confidentiality of information is guaranteed.

5.3 To ensure older persons have access to information about available care and support services, including assistive technologies, so they can effectively use, select and opt out of care and support services.

5.4 To ensure older persons have access to information and training on the use of assistive technologies, including digital and technical skills, so that they can evaluate the risks and benefits of different care and support services and make informed decisions based on this.

**Redress**

6. States Parties shall take effective and appropriate measures

6.1 To ensure older persons have access to effective dispute resolution, complaint mechanisms and administrative and or judicial processes to seek redress for practices that restrict their liberty and autonomy and do not respect their will and preferences or in situations where violations occur.

6.2 To ensure older persons have access to effective compliance mechanisms for complaints arising out of a range of issues including pricing, quality, and the protection of human rights in care.

**Financing**

7. States Parties shall take effective and appropriate measures

7.1 To develop and implement policies to address public and private financing of care and support services.

7.2 To ensure older persons are not denied necessary and appropriate care and support services based on their and/or their family’s financial means.

**2. Normative elements of the right of older persons to palliative care**

1. Older persons have the right to quality palliative care services.

1.1 Older persons have the right to quality palliative care services that are available, accessible, and acceptable without discrimination of any kind.

1.2 Older persons have the right to holistic palliative care which is not limited to pain relief or any particular treatment or setting.

1.3 Older persons have the right to give and withdraw at any time their free, prior, on-going and informed consent to their palliative care treatment and any other health matters.

2. States Parties shall take effective and appropriate measures

2.1 To ensure quality palliative care services are available, accessible and acceptable for older persons.

2.2 To make available and accessible essential medicines and technologies, including internationally controlled essential medicines, for the treatment of moderate to severe pain, and for palliative care of older persons.

2.3 To prevent cruel, inhuman and degrading treatment of older persons, including as a result of the failure to adequately treat pain and other symptoms.

2.4 To ensure older persons have timely access to information about all aspects of their health and palliative care treatment options so they are able to express their free, prior, on-going and informed consent to their palliative care treatment and any other health matters.

2.5 To ensure older persons have access to palliative care in a setting that is consistent with their needs, will and preferences, including, but not limited to, in the home, in hospices, in hospital, and in other care and support settings.

2.6 To put in place processes for supported decision-making where necessary, whilst

retaining legal capacity.

2.7 To establish procedures by which older persons may prepare 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, including the place palliative care services are provided.

2.8 To ensure older persons have access to a range of supports to exercise their legal capacity, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences.

2.9 To ensure access to support for family members and others close to the older person, including bereavement support.

2.10 To ensure narcotic drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering.

2.11 To review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes.

2.12 To remove regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications.

2.13 To ensure measures are in place to safeguard against the misuse of narcotic and psychotropic drugs and other medications.

2.14 To integrate palliative care into public health and social care systems, including care and support services for older persons.

2.15 To ensure the adequate and appropriate training of health, social and spiritual care providers, including volunteers, in palliative care.

2.16 To regulate and monitor of compliance of all palliative care providers with

professional obligations and standards.

**Annex 1: Normative basis of the right of older persons to care and support for independent living**

**International**

**International Covenant on Political and Civil Rights, 1966**

Article 9.1: Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

**Convention on the Rights of Persons with Disabilities, 2006**

*Article 19 (Living independently and being included in the community)*

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom to live on an equal basis with others and are not obliged to live in any particular living arrangement;

b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

**United Nations Principles for Older Persons, Adopted by General Assembly resolution 46/91 of 16 December 1991**

"**Care**

(10) Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.

(11) Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.

(12) Older persons should have access to social and legal services to enhance their autonomy, protection and care.

(13) Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.

(14) Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives."

**Regional**

**Inter-American Convention on Protecting the Human Rights of Older Persons, 2015**

Article 12: Rights of older persons receiving long-term care

Older persons have the right to a comprehensive system of care that protects and promotes their health, provides social services coverage, food and nutrition security, water, clothing, and housing, and promotes the ability of older persons to stay in their own home and maintain their independence and autonomy, should they so decide*.*

States Parties shall design assistance measures for families and caregivers through the introduction of services for those providing care to older persons, taking into account the needs of all families and other forms of care, as well as the full participation of older persons and respect for their opinions.

States Parties shall adopt measures toward developing a comprehensive care system that takes particular account of a gender perspective and respect for the dignity, physical, and mental integrity of older persons.

In order to ensure that older persons can effectively enjoy their human rights when receiving long-term care, States Parties undertake to:

a)  Establish mechanisms to ensure that the initiation and conclusion of long-term care services are subject to an indication by the older person of their free and express will.

b)  Ensure that such services have specialized personnel who can provide appropriate, comprehensive care and prevent actions or practices that could cause harm or exacerbate an existing condition.

c)  Establish an appropriate regulatory framework on the operations of long-term care services that allows the situation of older persons to be assessed and supervised, as well as the adoption of measures to:

1. Ensure access for older persons to information, especially to their own physical or digital records, promote their access to the various media and sources of information, including social networks, and apprise them of their rights and of the legal framework and protocols governing long-term care services.
2. Prevent arbitrary or illegal intrusions in their private life, family, home, household unit, or any other sphere in which they are involved, or in their correspondence or any other form of communication.
3. Promote older persons’ interaction with their family and society, bearing in mind all families and their affective relationships.
4. Protect older persons’ personal security and the exercise of their personal liberty and freedom of movement.
5. Protect the integrity of older persons as well as their privacy and intimacy in all their activities, particularly in acts of personal hygiene.

d)  Enact the necessary legislation, in accordance with domestic mechanisms, so that the corresponding personnel and long-term care givers may be held liable to administrative, civil, and/or criminal penalties, as applicable, for any acts they commit that cause harm to older persons.

e)  Adopt appropriate measures, as applicable, to ensure that older persons receiving long-term care also have palliative care available to them that encompasses the patient, their environment, and their family.

**Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons in Africa, 2016**

Article 10: Care and Support

States Parties shall:

1. Adopt policies and legislation that provide incentives to family members who provide home care for Older Persons;
2. Identify, promote and strengthen traditional support systems to enhance the ability of families and communities to care for Older family members; and
3. Ensure the provision of preferential treatment in service delivery for Older Persons.

Article 11: Residential Care

States Parties shall:

1. Enact or review existing legislation to ensure that residential care is optional and affordable for Older Persons;
2. Ensure that Older Persons in residential care facilities are provided with care that meets the National Minimum Standards provided that such standards comply with regional and international Standards; and
3. Ensure that Older Persons in palliative care receive adequate care and pain management medication.

**European Social Charter**

Article 23: The right of elderly persons to social protection

With a view to ensuring the effective exercise of the right of elderly persons to social protection, the Parties undertake to adopt or encourage, either directly or in co-operation with public or private organisations, appropriate measures designed in particular:

* to enable elderly persons to remain full members of society for as long as possible, by means of:

a. adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life;

b. provision of information about services and facilities available for elderly persons and their opportunities to make use of them;

* to enable elderly persons to choose their life-style freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of:

a. provision of housing suited to their needs and their state of health or of adequate support for adapting their housing;

b. the health care and the services necessitated by their state;

* to guarantee elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

**Council of Europe recommendation CM/Rec(2014)2**

VI.        Care

*A. General Principles*

29.       Member States should take appropriate measures, including preventive measures, to promote, maintain and improve the health and well-being of older persons. They should also ensure that appropriate health care and long-term quality care is available and accessible.

30.       Services should be available within the community to enable older persons to stay as long as possible in their own homes.

31.       In order to better assess and fulfil the needs of older persons, member States should promote a multi-dimensional approach to health and social care for them and encourage co-operation amongst the competent services.

32.       Care providers should treat any sensitive personal data of older persons confidentially and carefully in accordance with their right to privacy.

33.       Care should be affordable for older persons and programmes should be in place to assist older persons, if necessary, with covering the costs.

34.       Care givers should receive sufficient training and support to adequately ensure the quality of the services provided. Where older persons are being cared for at home by informal carers, the latter should likewise receive sufficient training and support to ensure that they are able to deliver the care needed.

35.       Member States should operate a system through which care delivery is regulated and assessed.

***C. Residential and institutional care***

40.       Member States should provide for sufficient and adequate residential services for those older persons who are no longer able or do not wish to reside in their own homes.

41.       Older persons who are placed in institutional care have the right to freedom of movement. Any restrictions must be lawful, necessary and proportionate and in accordance with international law. There should be adequate safeguards for review of such decisions. Member States should ensure that any individual constraints for an older person should be implemented with the free and informed consent of that person, or as a proportionate response to a risk of harm.

42.       Member States should ensure that there is a competent and independent authority or body responsible for the inspection of both public and private residential institutions. Member States should provide for easily accessible and effective complaint mechanisms and redress for any deficiencies in the quality of care.

43.       Older persons in principle should only be placed in residential, institutional or psychiatric care with their free and informed consent. Any exception to this principle must fulfil the requirements of the European Convention on Human Rights, in particular the right to liberty and security (Article 5).

**Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 1997**

Chapter II – Consent

Article 5 – General rule

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.

**Annex 2: Normative basis of the right of older persons to palliative care**

**International**

**Advisory documents**

**Committee on Economic, Social and Cultural Rights General Comment No. 14 (2000)**

34. In particular, States are under the obligation to *respect* the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum-seekers and illegal immigrants, to preventive, curative and palliative health services; …

**Committee on the Elimination of Discrimination Against Women, General Recommendation No. 27, (2010)**

45. States parties should adopt a comprehensive health care policy for the protection of the health needs of older women in keeping with General Recommendation 24 on women and health. This should ensure affordable and accessible health care to all older women through, where appropriate, the elimination of user fees for them, the training of health workers in geriatric illnesses, the provision of medicine to treat age-related chronic and non- communicable diseases, long term health and social care, including care that allows for independent living, and palliative care.

**Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/10/44, 2009** 72. Similarly, the Special Rapporteur is of the opinion that the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.

**Report of the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53, 2013**

54. Generally, denial of pain treatment involves acts of omission rather than commission, and results from neglect and poor Government policies, rather than from an intention to inflict suffering. However, not every case where a person suffers from severe pain but has no access to appropriate treatment will constitute cruel, inhuman, or degrading treatment or punishment. This will only be the case when the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment; when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps to protect individuals‟ physical and mental integrity.

86. The Special Rapporteur calls upon all States to:

(a) Adopt a human rights-based approach to drug control as a matter of priority to prevent the continuing violations of rights stemming from the current approaches to curtailing supply and demand (A/65/255, para. 48). Ensure that national drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering; review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical uses;

(b) Ensure full access to palliative care and overcome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine. States should devise and implement policies that promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use;

(c) Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols.

**Report of the Independent Expert on the enjoyment of all human rights by older persons, A/HRC/30/43, 2015**

87. The Independent Expert stresses that the Special Rapporteur on the right to health and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment qualified the failure to ensure access to controlled medicines for the relief of pain and suffering as a threat to the fundamental right to health and the right to be free from cruel, inhuman and degrading treatment.

131.The right to palliative care should be enshrined in the legal framework so that older persons can enjoy the last years of their lives in dignity and without unnecessary suffering. States should ensure the availability and accessibility of palliative care for all older persons in need, particularly those who suffer from a life-threatening or life-limiting illness. Training, and adequate and affordable medication and therapeutic measures, should be provided in public and private care settings.

**Regional**

**Inter-American Convention on Protecting the Human Rights of Older Persons, 2015**

“Palliative care”: Active, comprehensive, and interdisciplinary care and treatment of patients whose illness is not responding to curative treatment or who are suffering avoidable pain, in order to improve their quality of life until the last day of their lives. Central to palliative care is control of pain, of other symptoms, and of the social, psychological, and spiritual problems of the older person. It includes the patient, their environment, and their family. It affirms life and considers death a normal process, neither hastening nor delaying it.

Article 6 Right to life and dignity in old age

States Parties shall adopt all measures necessary to ensure older persons’ effective enjoyment of the right of life and the right to live with dignity in old age until the end of their life and on an equal basis with other segments of the population.

States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care; avoid isolation; appropriately manage problems related to the fear of death of the terminally ill and pain; and prevent unnecessary suffering, and futile and useless procedures, in accordance with the right of older persons to express their informed consent.

Article 11 Right to give free and informed consent on health matters

States Parties shall also establish a procedure that enables older persons to expressly indicate in advance their will and instructions with regard to health care interventions, including palliative care. In such cases, that advance will may be expressed, amended, or expanded at any time by the older person only through legally binding instruments in accordance with domestic law.

Article 12 Rights of older persons receiving long-term care

e) Adopt appropriate measures, as applicable, to ensure that older persons receiving long-term care also have palliative care available to them that encompasses the patient, their environment, and their family.

Article 19 Right to health

Older persons have the right to physical and mental health without discrimination of any kind.

States Parties shall design and implement comprehensive-care oriented intersectoral public health policies that include health promotion, prevention and care of disease at all stages, and rehabilitation and palliative care for older persons, in order to promote enjoyment of the highest level of physical, mental and social well-being. To give effect to this right, States Parties undertake to: …

j) Promote and strengthen research and academic training for specialized health professionals in geriatrics, gerontology, and palliative care.

l) Promote the necessary measures to ensure that palliative care services are available and accessible for older persons, as well as to support their families.

m) Ensure that medicines recognized as essential by the World Health Organization, including controlled medicines needed for palliative care, are available and accessible for older persons.

**Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons in Africa, 2016**

Article 11 Residential Care

3. Ensure that Older Persons in palliative care receive adequate care and pain management medication.

**Council of Europe recommendation CM/Rec(2014)2**

D. Palliative care

44. Member States should offer palliative care to older persons who suffer from a life- threatening illness or an illness limiting their life expectancy, to ensure their well-being and allow them to live and die with dignity.

45. Any older person who is in need of palliative care should be entitled to access it without undue delay, in a setting which is consistent with his or her needs and preferences, including at home and in long-term care settings.

46. Family members and friends should be encouraged to accompany older persons who are terminally ill or dying. They should receive professional support, for example by ambulatory palliative-care services.

47. Health care providers involved in palliative care should fully respect patients’ rights, and comply with professional obligations and standards.

48. Trained specialists in the field of palliative care should be available to lead education and research in the field. Programmes of palliative care education should be incorporated into the training of all health and social care workers concerned, and co-operation between professionals in palliative care should be encouraged.

49. Member States should ensure the adequate availability and accessibility of palliative care medicines.

50. In the organisation of their national palliative care systems, member States should take into account Committee of Ministers Recommendation Rec(2003)24 to member States on the organisation of palliative care.

**Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 1997**

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