

Joint submission by AGE Platform Europe, HelpAge International, The Law in the Service of the Elderly and the National Association of Community Legal Centres Australia¹

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Normative elements of the right to care and support for independent living and to palliative care

Authors

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Question 2: Normative elements

Normative elements of the right to care and support for independent living

Affirmation

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 and maintain their autonomy and independence, without discrimination of any kind.

Scope

1.1 The right applies 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.

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

State obligations

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.

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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 advance instructions 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 support 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 persons 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.

Normative elements of the right to palliative care

Affirmation

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

Scope

1.1 The right applies to holistic palliative care in all settings and is not limited to pain relief or any particular treatment or setting.

State obligations

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, 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 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 at home and in long-term care 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, especially oral morphine.

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 the public health system.

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

2.16 To regulate and monitor compliance of all palliative care providers with professional obligations and standards.