

Autonomy, independence, long-term care and palliative care: A discussion paper for the 9th Open-ended Working Group on Ageing

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1. Introduction

This discussion paper has been developed by an informal group brought together on their own initiative to respond to the call of the Chair of the UN Open-ended Working Group on Ageing (OEWG) inviting stakeholders to contribute ideas and proposals on the possible elements of a new international instrument. The group comprises a small number of representatives of NGOs and legal experts with the immediate goal to provide input that will support the work of civil society as well as help frame the discussion at the OEWG.

As a self-appointed group, it cannot reflect the diversity of the stakeholders involved in the OEWG whose opinions need to inform the next steps. Neither do its views necessarily build on the broad and consensual positions of the organisations that its members represent.

Members of this informal group who have contributed to this paper are (in alphabetical order): Robin Allen (Cloisters), Andrew Byrnes (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 Sleep (HelpAge International).¹

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¹ For further information contact Bridget Sleep bsleep@helpage.org

2. Autonomy and independence

2.1 Definitions and concepts

Autonomy

Autonomy is the ability to make choices and decisions, including with support if necessary, according to one's conscience, values, will and preferences.

The exercise of autonomy is necessary for human dignity. Autonomy is both an underlying principle that governs every human right and a right in and of itself. The principle of autonomy presumes that individuals are able to make choices according to their own will and preferences. The WHO reinforced the importance of autonomy in its World Report as *"Retaining the ability and right to choose is closely linked to notions of agency and autonomy, which have been shown to have a powerful influence on an older person's dignity, integrity, freedom and independence"*.²

In order to make autonomous decisions, and for these decisions to be legally effective, the law requires that the individual has the legal capacity to do so. To enjoy their right to autonomy therefore, older persons must enjoy legal capacity on an equal basis with others. Where legal safeguards are not in place, it is possible for a relevant authority to presume an older person does not have legal capacity based on ageist notions and prejudices. This form of discrimination or 'benevolent prejudice' is deeply embedded in many societies.

The exercise of autonomy applies to every aspect of life, including where and with whom to live, one's own life plans and well-being,³ private and family life,⁴ and participation in social, cultural, spiritual, public, political, educational, training and leisure activities.⁵ It should not be assumed that older persons are not interested in, or do not want to participate in, wider community, social and political life.

Independence

Independence is the ability to perform actions of daily living and participate in society in accordance with one's will, values and preferences.

Independence does not necessarily mean living alone or doing all daily activities by or for oneself. Rather independence is having choice and control over decisions about one's own life, including control over decisions which lead to the execution of tasks that someone else carries out. Independence also means not being deprived of the opportunity of choice and control to make decisions, including when support or care is needed. Independence also requires that the environment is universally designed and barrier free.

The recognition of the centrality of autonomy and independence does not negate the realisation of inter-dependence of human existence and the nature of inter-relationships of care and dependence throughout the life course. It rather points to the over-arching values and principles which should govern these human interactions, especially in older age.

² WHO, *World Report on Ageing and Health*, 2015, page 35

³ See Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Article 7; Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, 2016, Article 5

⁴ Council of Europe recommendation CM/Rec(2014)2, III. Autonomy and participation, paragraph 11

⁵ See Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Article 7; Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, 2016, Article 5.3; Council of Europe recommendation CM/Rec(2014)2, III. Autonomy and participation, paragraph 10

Paradigm shift required

A paradigm shift is required away from ageist attitudes that devalue, discount or ignore the views and choices of older persons, or assume older persons can no longer make, and are thereby denied the opportunity to make, decisions for themselves.

The shift must presume older persons can exercise their autonomy and independence through choice and control over decisions in their lives in line with their will and preferences. The best safeguard for autonomy, independence and legal capacity is respect for will and preferences. The use of the 'best interests' principle in respect of adults is not a safeguard that complies with international human rights norms.

This paradigm shift requires us also to change the social construction of human dignity in older age whereby dignity in older age is not centred around protection, intervention and professional care in the 'best interest' of the older person. Rather, dignity in older age means respecting autonomy and ensuring independence for each individual in their own right in older age.

2.2 Normative basis

Whilst the right to equal recognition before the law⁶ and the right to a family and private life⁷ are enshrined in international human rights law, the rights to autonomy and independence and support for independent living are newly emerging in the application of human rights in the context of older age.⁸ Concerns have also emerged around the denial of older persons' free and informed consent in areas such as control of one's own living arrangements, pension or other income or assets, who to leave one's property to, medical treatment, restrictive interventions and practices, and end of life treatment.⁹

International human rights law

- Universal Declaration of Human Rights, 1948, Article 6 & Article 12
- International Covenant on Political and Civil Rights, 1966, Article 16 & Article 17: 1
- Convention on the Rights of Persons with Disabilities, 2006, Article 5.1, Article 12
- Article 22.1 & Article 23.1

Regional human rights law on the rights of older persons

- Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Article 7, Article 11
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, 2016, Article 5
- The EU Charter of Fundamental Rights, 2000, Article 25
- European Social Charter, Article 23

⁶ For example UDHR, Article 6; ICCPR, Article 16; CRPD Article 5.1

⁷ For example UDHR, Article 12; ICCPR Article 17; CRPD Articles 22 and 23

⁸ ECLAC, *Challenges to the autonomy and interdependent rights of older persons*, 2017, page 81

⁹ Office of the High Commissioner for Human Rights, *Normative standards in international human rights law in relation to older persons, Analytical Outcome Paper*, 2012, page 22. See also Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Article 11; Council of Europe recommendation CM/Rec(2014)2 B. *Consent to medical care*

2.3. Normative elements of the right to autonomy and independence

- **Affirmation of the right**

Older persons have the right to freedom of personal autonomy and legal capacity to make decisions, to determine their life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. This includes the right to have those decisions respected.

- **Scope of the right**

Older persons have the right to autonomy, self-determination, control and choice in all aspects of their life, including but not limited to making decisions about their support and assistance; leisure time; property; income; finances; place of residence and living arrangements; health and medical treatment or care; end of life care; personal, family and private life, including sexual and intimate relationships; social and political participation and, funeral and burial arrangements.

Older persons have the right to interact with others and full, effective and meaningful participation in family, social, cultural, economic, public and political life and educational and training activities.

Older persons have the right to live independently in the community on an equal basis with others. This includes the right to choose where and with whom they live and not to be obliged to live in any particular living arrangement.

When, and to the extent to which, older persons freely choose to live in shared residential settings, they maintain their rights to autonomy, independence, control and choice and these must be respected.

- **State obligations**

States Parties shall take steps and measures to ensure:

- Older persons have access to services, including support to exercise legal capacity, which enable them to exercise their right to autonomy and independence including support necessary for them to make, communicate and participate in decisions.
- Mechanisms designed to enable the exercise of older persons' right to autonomy and independence recognize older persons' right to legal capacity on an equal basis with others in all aspects of life.
- Older persons have access to a range of support services in order to support independent living and inclusion in the community, and to prevent isolation or segregation from the community. Such support should be available on an equal basis in home, community and residential settings to ensure older persons' enjoyment of their right to choose where and with whom they live.
- Older persons living in shared residential settings are provided with specific and tailored support services to exercise their right to autonomy and independence in order to accommodate the cultural, spiritual, professional and environmental challenges of these facilities.
- 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.
- Community services and facilities for the general population are available on an equal basis to older persons and are responsive to their needs.

2.4 Normative elements of the right to equal recognition before the law

- **Affirmation of the right**

Older persons everywhere and at all times have legal capacity and the right to equal recognition before the law on an equal basis with others.

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 instructions, will and preferences may not be easily understood by others.

Older persons have the right to make advance directives to express their will and preferences in advance, so they can be followed at a time when the older person may not be in a position to communicate them.

Older persons have the right to participate in, and challenge, any decisions that interfere with the exercise of their legal capacity, including decisions that seek to substitute, or offers or requests to support, their decision-making.

- **Scope of the right**

Older persons have legal capacity on an equal basis with others in all aspects of life including, but not limited to, decisions about their support services; leisure time; property; income; finances; place of residence and living arrangements; health and medical treatment or care; end of life care; personal, family and private life, including sexual and intimate relationships; electoral voting; political participation; and, funeral and burial arrangements.

- **State obligations**

State Parties shall take steps and measures to ensure:

- Older persons have access to the mechanisms and support they may require to exercise their legal capacity in accordance with their will and preferences, and on an equal basis with others.
- Older persons have access to appropriate and effective safeguards to prevent abuse in the exercise of their legal capacity, and to respect their will and preferences in accordance with international human rights law, including the right to legal counsel; and which are free of conflict of interest and undue influence and are tailored to the older person's circumstances.
- Effective access to justice and redress for older persons including through provision of procedural accommodations and special measures to prevent unnecessary delay in the legal process.
- Appropriate training in this area for support and trusted persons, support and other service providers, including but not limited to notaries and medical personnel, and those working in the administration of justice, including police and prison staff.

3. Long-term care: the right to care and support for independent living

3.1. Definitions and concept

Long-term care

'Long-term care' has been defined as:

'the activities undertaken by others to ensure that people with a significant on-going loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.' WHO¹⁰

'day-to-day help with activities such as washing and dressing, or help with household activities such as cleaning and cooking. This type of support (along with some types of medical care) is what is called long-term care.' OECD¹¹

Living independently

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.

Support

Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society.¹² 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 and independence in older age.

The exercise of autonomy and independence necessitates a person-centred approach to long-term care rather than a system-based approach. This means that the will and preferences of older people who require support are the moral foundation and justification for decisions about their support and not the support system itself. This is essential to ensure that the different options available to older people are adequate and reflect their views, preferences and values.

The support older people may require to carry out daily activities and participate in society includes both live assistance and intermediaries, and assistive devices and technologies, such as:¹³

- Mobility support, such as assistive technology or service animals
- Communication support
- Support for daily activities such as eating, dressing, personal hygiene and sanitation, visiting friends, going shopping, participating in leisure activities, and participating in other social, religious, cultural, political or educational activities and personal relationships on an equal basis with others.
- Support in decision-making, including the possibility of advance decision making, in relation to, inter alia, budgeting and financial planning, the making of wills, healthcare, and end of life care
- Support to ensure decent employment
- Living arrangement services for securing housing and household help

¹⁰ WHO, *World Report on Ageing and Health*, 2015, page 229

¹¹ OECD <http://www.oecd.org/els/health-systems/long-term-care.htm>

¹² Report of the Special Rapporteur on the rights of person with disabilities, December 2016, A/HRC/34/58, paragraph 13

¹³ See A/HRC/34/58, para 14 and CRPD General Comment No. 5 on Article 19

- Community services
- Support to access and use services available to the general public such as health, education, transport and justice
- Support to participate in the design and development of policies and support services to meet their needs
- Support in the use of new technologies and scientific developments

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. The ILO estimates that globally, 13.6 million more formal support providers are needed to provide the support older people need.¹⁴

Support may not be guaranteed under the law. Only 5.6 % of the world's population lives in a country with national legislation providing universal entitlements to support services.¹⁵

Some types of support, for example, personal assistance schemes, may be subject to upper age limits and therefore not available to older persons.¹⁶

Support may also be unaffordable or tied to particular living arrangements. Some 'filial responsibility' laws¹⁷ oblige adult children to financially support or fund their older relative's support needs and/or include the income of the adult children as part of the assessment for receiving publicly funded support services. Another concern is that financing may be available for some support needs, and not others.

Violation of rights: Restrictive practices

One area of particular concern that has not been sufficiently addressed is the use of restrictive interventions and practices to manage challenging behaviour in long-term care and support settings.¹⁸ This can include the use of restrictive practices within in-home care settings. This is particularly important given the increasing need to address the human rights of persons with dementia who are often subject and vulnerable to restrictive practices.

Restrictive practices include seclusion, surveillance, the use of tagging systems, close observation, exclusionary time out and consequence-driven restrictive practices. They may be physical, chemical, mechanical, psychosocial, environmental or technological. 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 other unnecessary medication to restrict/subdue behaviour).¹⁹

¹⁴ Scheil-Adlung, *Extension of Social Security: Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ESS-Working Paper No. 50, ILO, 2015, page xii

¹⁵ Scheil-Adlung, *Extension of Social Security: Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ESS-Working Paper No. 50, ILO, 2015, page xi

¹⁶ See Age Platform Europe, http://age-platform.eu/sites/default/files/AGE_input_Draft_GCArt5_CRPD.pdf

¹⁷ See for example Law of the People's Republic of China on Protection of the Rights and Interests of the Elderly.

¹⁸ See for example Office of the Public Advocate Queensland, *Legal frameworks for the use of restrictive practices in residential aged care: A an analysis of Australian and international jurisdictions*, 2017

¹⁹ Australian Law Reform Commission, *Elder Abuse – A National legal Response*, ALRC Report 131, May 2017, p. 251.

These practices amount to violations of human rights including the deprivation of liberty, restriction of free movement, breach of privacy and assault, abuse and denial of autonomy and independence. Robust regulation and monitoring of care and support services in all settings is necessary to ensure the elimination of such practices. In addition, more attention needs to be given to the practical application of human rights in care and support settings.

Living in the community

Isolation, social exclusion, segregation and loneliness can affect older persons regardless of their particular living arrangements. The impacts of these factors on health can be catastrophic including contributing to or exacerbating multi-morbidity and a substantial reduction in life expectancy. Isolation, social exclusion and segregation of older persons also contributes to ageism.

Inclusion and participation requires that all services offered to the general public are offered to older persons without discrimination. These services may relate, inter alia, to housing, transport, shopping, education, employment, volunteering, leisure, recreational activities and technology. Living in the community also includes, having access to all measures and events of political and cultural life in the community, among others voting in elections, public meetings, sports events, cultural and religious festivals and any other activity in which the older person wishes to participate.²⁰

Living in the community requires meaningful opportunities for inter-generational exchange and activities, where both older and younger people participate on an equal basis.

Paradigm shift required

A paradigm shift is necessary away from an approach to long-term care that excludes and disconnects older persons from their communities and denies them their autonomy and independence and moves to an approach of full integration in the community whereby older persons have the right and access to individualized support and assistance which enable them to exercise choice and control over their lives and their care and support at home, in community or in residential settings.

3.2 Normative basis

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 law²¹ are pertinent in long-term care settings but their specific application in this area has yet to be fully explored.

The Convention on the Rights of Persons with Disabilities, 2006, Article 19, provides for the right to independent living for older persons with disabilities, which includes the provisions of support services to enable such independent living.

²⁰ See CRPD, General Comment no.5, General comment on article 19: Living independently and being included in the community, CRPD/C/GC/5, September 2017

²¹ For example, non-discrimination (ICCPR Art 26); the right to life (ICCPR Art 6); the right to liberty and security of person (ICCPR Art 9); the right to health (ICESCR Art 12); the right to an adequate standard of living (ICESCR Art 11); the right to social security (ICESCR Art 9); the right of persons with disabilities to live independently with the community (CRPD Art 19); the right to freedom of expression and information (ICCPR Art 19); equal recognition before the law (ICCPR Art 16); and, the right to access to justice and redress (ICCPR Art 2).

The Optional Protocol to the Convention against Torture (OP-CAT) establishes the Sub-Committee for the Prevention of Torture (SPT) and requires States to designate or establish independent National Preventive Mechanisms (NPM) and sets out their mandate to visit any place where persons are deprived of liberty.²² Social care institutions are listed as one of the places of detention that the SPT can visit.²³ This creates the potential for independent inspections of long term care institutions. Despite this, the application of OPCAT is potentially limited in its scope since it may not apply to in-home care, even if the care worker is employed by a service provider who also provides residential care.

Institutionalization can happen in any setting, including in the home. All people are protected from arbitrary deprivation of their liberty under Article 9.1 of the International Covenant on Civil and Political Rights but such safeguards against institutionalisation in international law have been criticised as being inadequate.²⁴ Age should never be used as a basis for deprivation of liberty, alone or in combination with other factors including perceived risk of harm to the older person.

Similarly, there has been little demonstrable effort by States parties or Treaty Bodies to interpret and apply the prohibition on torture, cruel, inhuman or degrading treatment in the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment to older persons living in long-term care settings.²⁵

Provisions at the regional level establish long-term care as a justiciable right but are limited and vary in scope and the strength of protection they provide.²⁶ The Inter-American Convention on Protecting the Human Rights of Older Persons affirms in Article 12 that older persons have the right to a comprehensive system of care that not only protects and promotes their well-being but also maintains their independence and autonomy. However, the coverage of provisions related to long term care in Article 12 are limited by the Convention's definition in Article 2 of an 'older person receiving long term care services' as being someone 'who resides temporarily or permanently in a regulated, public, private or mixed establishment'. They do not, therefore, apply to someone receiving long-term care and support services in their own home.

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa establishes only limited State obligations in relation to care and support in home and residential settings. The Council of Europe recommendation CM/Rec(2014)2 makes recommendations on both home and residential care settings but does not establish long term care as a right.

Practice and jurisprudence of the human rights treaty bodies and special procedures

The Committee on Economic, Social and Cultural Rights recommends in its the General Comment No. 6 (2006) that State parties should provide social services to support older

²² A/RES/57/199

²³ *The SPT in Brief*, Office of the High Commissioner for Human Rights, <http://www.ohchr.org/EN/HRBodies/OPCAT/Pages/Brief.aspx> (11 May 2016); SCPT, Sixth annual report of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, CAT/C/50/2, para 67 (2013).)

²⁴ Office of the High Commissioner for Human Rights, *Normative standards in international human rights law in relation to older persons*, pp.8 - 9

²⁵ Office of the High Commissioner for Human Rights, *Normative standards in international human rights law in relation to older persons*, p.9

²⁶ ECLAC, *Challenges to the autonomy and interdependent rights of older persons*, 2017, page 137

persons who live with family members or who live alone and to older couples who prefer to stay in their own home.

The Committee on Economic, Social and Cultural Rights' General Comment No. 14 reiterates the need for preventive, curative, and psychological and physical rehabilitative health treatment for older persons. States parties should also pay attention to care for the chronically and terminally ill, sparing them avoidable pain and enabling them to die with dignity.²⁷

The Committee on the Elimination of Discrimination against Women's General Recommendation No. 27 (2010) recommends that States parties adopt a comprehensive health care policy aimed at protecting the health care needs of older women including social care and care that allows for independent living and palliative care.²⁸

The Committee against Torture's General Comment No. 2 specifically refers to the obligation on States parties to "*prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example in...institutions that engage in the care of...the aged*".²⁹

The Independent Expert on the enjoyment of all human rights by older persons recommended that states should provide long-term care through a comprehensive and inter-sectoral approach along with recommendations on the inclusion of older persons in the design and evaluation of care services, provision of support to informal and family caregivers, revision of legislation and settings of standards to prevent forced institutionalisation, monitoring and regulation systems, and the development of home and community-based care services.³⁰

International human rights law

- International Covenant on Political and Civil Rights, 1966, Article 9.1
- Convention on the Rights of Persons with Disabilities, 2006, Article 19

Regional human rights law on the rights of older persons

- Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Article 12
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, 2016 , Article 10 & Article 11:
- European Social Charter, Article 23

Regional advisory documents

- Council of Europe recommendation CM/Rec(2014)2, VI.Care

²⁷ E/C.12/2000/4, CESCR, 2000, paragraph 25

²⁸ CEDAW/C/GC/27, CEDAW, 2010, paragraph 45

²⁹ CAT/C/GC/2, CAT, 2008. paragraph 15

³⁰ A/HRC/30/43, IE Older Persons, paragraphs 115 - 123

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

- **Affirmation of the right**

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 of the right**

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.

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**

States Parties shall take steps to ensure:

Autonomy

- The availability of, and older persons' access to, 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.
- Older persons have choice and control over care and support services which are adapted to their individual needs and preferences.
- Older persons have access to mechanisms, including supported-decision making, which enable them to exercise their right to autonomy and independence.
- 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.
- Older persons have control over the planning, delivery and monitoring of their care and support, including access to support with decision-making where necessary.
- Older persons can opt out of the care and support service at any time.
- 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.
- 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

- 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.
- Older persons have the opportunity to participate in the design, development and evaluation of assistive technologies and devices.
- 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

- Research, design, development and monitoring of care and support services with involvement of older people themselves, including assistive technologies, should be carried out in accordance with international ethical research standards.
- Quality standards for care and support services are based on human rights principles.
- Regulation, monitoring and enforcement of 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.
- 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.
- Appropriate resourcing, training of care and support service providers and public awareness to safeguard the rights of older persons receiving care and support in any setting.

Redress

- 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.

Information

- Older persons have access to information about their health status so their decisions can be free, prior and informed.
- The confidentiality of information is guaranteed.
- 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.
- 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.

Financing

- Development and implementation of policies to address public and private financing of care and support services.
- Older persons are not denied necessary and appropriate care and support services based on their and/or their family's financial means.

4. Palliative care

4.1 Definitions and concept

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.³¹ It also addresses the psychosocial, legal and spiritual aspects associated with life-threatening illnesses.³²

The World Health Organization defines palliative care as *'an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.'*³³

4.2 Normative basis

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 establish this right. Access to palliative care is both a component of the right to the highest attainable standard of health³⁴ and implicates the right to freedom from cruel, inhuman and degrading treatment.³⁵

The UN Committee on Economic, Social and Cultural Rights has asserted *'States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons...to preventive, curative and palliative health services.'*³⁶ It has further defined access to essential medicines, as established by WHO, as part of the "minimum core content" of the right to the highest attainable standard of health,³⁷ and twenty palliative care medicines are currently on WHO's essential medicines list.³⁸ The Committee has also called for *'attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.'*³⁹ The UN Committee on the Elimination of Discrimination against Women has called upon States to *'adopt a comprehensive health-care policy aimed at protecting the health needs of older women,'* which includes accessible palliative care.⁴⁰

The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has stated that that limiting equal access of all

³¹ UN General Assembly, *Report of the Special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A.65/255, August 6th 2010

³² Open Society Foundations, *Palliative Care as a Human Right*, 2016, <https://www.opensocietyfoundations.org/publications/palliative-care-human-right-fact-sheet>

³³ <http://www.who.int/mediacentre/factsheets/fs402/en/>

³⁴ International Covenant on Economic, Social and Cultural Rights, Article 12

³⁵ International Covenant on Civil and Political Rights, Article 7

³⁶ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, E/C.12/2000/4, 2000, paragraph 34

³⁷ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, E/C.12/2000/4, paragraph 12

³⁸ WHO, Model List of Essential Medicines, 19th List, 2015, <http://www.who.int/medicines/publications/essentialmedicines/en/>

³⁹ UN Committee on Economic, Social and Cultural Rights, General Comment 14, 2000, E/C.12/2000/4, paragraph 25

⁴⁰ UN Committee on the Elimination of Discrimination against Women, General Recommendation No. 27, 2010 CEDAW/C/GC/27, paragraph 45

persons to palliative care on the basis of age cannot be considered appropriate and may amount to discrimination on the basis of age.⁴¹ Furthermore, states should protect patients' rights to make autonomous, informed decisions regarding access to pain relief, location of death and refusal of treatment designed to prolong life if this is against their wishes so that they can die with dignity.⁴²

The Independent Expert on the enjoyment of all human rights by older persons recommended that the right to palliative care should be enshrined in the legal framework and that states should ensure the availability and accessibility of palliative care in public and private settings.⁴³

In addition, two Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment have stated that denial of pain relief may constitute cruel, inhuman or degrading treatment.⁴⁴ In 2009, Professor Manfred Nowak, noted 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.*'⁴⁵ In 2013, the following Special Rapporteur, Professor Juan E. Mendez likewise asserted '*When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.*'⁴⁶

At the regional level, the Inter-American Convention on Protecting the Human Rights of Older Persons (2015) enshrines the right to palliative care in articles on the following rights: to life and dignity in old age (Article 6); to free and informed consent on medical matters (Article 11); to receive long-term care (Article 12), and to health (Article 19).

Article 11 on residential care in the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa (2016) recognizes the right of older persons in palliative care to receive adequate care and pain management medication.

The Council of Europe's Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons has a detailed section on necessary measures to realise the right to palliative care.⁴⁷

⁴¹ A/HRC/18/37, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 2011, Anand Grover, paragraphs 56 & 57 http://ap.ohchr.org/documents/alldocs.aspx?doc_id=18920 (27 July 2016)

⁴² A/HRC/18/37, SR Health, paragraph 59

⁴³ A/HRC/30/43, IE Older Persons, paragraphs 130 - 131

⁴⁴ A/HRC/10/44, 2009 and A/HRC/22/53, 2013

⁴⁵ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, January 14, 2009. <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf>, para. 72.

⁴⁶ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan Mendez, "Applying the torture and ill-treatment protection framework in health settings," A/HRC/22/53, February 1, 2013, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf, para. 55.

⁴⁷ CM/Rec(2014)2, paragraphs 44-50

Practice and jurisprudence of the human rights treaty bodies and special procedures

- Committee on Economic, Social and Cultural Rights General Comment No. 14 (2000), paragraphs 12, 25, 34
- Committee on the Elimination of Discrimination against Women, General Recommendation No. 27, (2010), paragraph 45
- Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, A/HRC/10/44, 2009, paragraph 72
- Report of the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, A/HRC/22/53, 2013, paragraph 51-56, 86
- Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43, 2015, paragraph 87, 131

Regional human rights law on the rights of older persons

- Inter-American Convention on Protecting the Human Rights of Older Persons, 2015, Articles 2, 6, 11, 12, 19
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, 2016, Article 11

Regional advisory documents

- Council of Europe recommendation CM/Rec(2014)2, D. Palliative care

4.3 Normative elements of the right to palliative care

• Affirmation of the right

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

• Scope of the right

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

States Parties shall take steps and measures to ensure:

- Quality palliative care services are available, accessible and acceptable for older persons.
- 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.
- Prevention of cruel, inhuman and degrading treatment of older persons, including as a result of the failure to adequately treat pain and other symptoms.
- Older persons are able to express their free, prior and informed consent to their palliative care treatment and any other health matters. Consent must be ongoing, not just obtained at the point of admission and/or commencement of the support service or palliative treatment.
- 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.
- Processes are in place for supported decision-making where necessary, whilst retaining legal capacity.
- Establishment of procedures by which older persons may prepare 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, including the place palliative care services are provided.

- 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 in circumstances where the older person's will and preferences may not be easily understood by others.
- Support for family members and others close to the older person, including bereavement support.
- Narcotic drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering.
- Review of national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes.
- Removal of regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine.
- The integration of palliative care into the public health system.
- Adequate and appropriate training of health, social and spiritual care personnel in palliative care.
- Regulation and monitoring of compliance of all palliative care providers with professional obligations and standards.