



Open-Ended Working Group on Ageing
Tenth working session

15–18 April 2019

**Substantive Inputs in the form of Normative Content for the
Development of a Possible International Standard on the Focus
Areas “Autonomy and Independence” and “Long-term and
Palliative Care”**

**Working document submitted by
the Department of Economic and Social Affairs (DESA)
in collaboration with the Office of the High Commissioner for Human
Rights (OHCHR)**

Table of Contents

	<u>Page</u>
I. Background.....	2
II. Autonomy and Independence.....	2
A. Overview of submissions.....	2
B. Conceptual basis.....	4
C. Specific issues.....	5
D. Definition.....	6
E. Affirmation of the right – possible normative elements.....	7
F. State obligations – possible normative elements.....	8
III. Long-Term Care.....	10
A. Relationship between the right to long-term care and the right to palliative care.....	10
B. Overview of submissions.....	10
C. Conceptual basis.....	11
D. Definition.....	12
E. Affirmation of the right to long-term care and support.....	12
F. State obligations – possible normative elements.....	13
IV. Palliative Care.....	15
A. Overview of submissions.....	15
B. Conceptual basis.....	16
C. Definition.....	16
D. Placement of a right to palliative care in any normative standard: freestanding or integrated in other rights.....	17
E. Affirmation of the right to palliative care.....	18
F. State obligations – possible normative elements.....	18
V. Conclusion.....	21

I. Background

1. The Open-Ended Working Group on Ageing, established by the General Assembly in its resolution 65/182 with the purpose of strengthening the protection of the human rights of older persons, will hold its tenth session at the United Nations Headquarters from 15 to 18 April 2019. Under item 6 of the Agenda¹, the Working Group will “follow-up to resolution 73/143: measures to enhance the promotion and protection of the human rights and dignity of older persons: best practices, lessons learned, possible content for a multilateral legal instrument and identification of areas and issues where further protection and action are needed.” To that end, the Bureau called for substantive inputs from Member States, national human rights institutions, non-governmental organisations and United Nations system agencies and bodies, in the form of normative content for the development of a possible international standard, following questionnaires prepared by the Secretariat on the two focus areas of the ninth session: “Autonomy and Independence” and “Long-Term and Palliative Care.”

2. During the tenth session, the Open-Ended Working Group on Ageing will consider and discuss the contributions received, based on the working document submitted by the Department of Economic and Social Affairs (DESA) in collaboration with the Office of the High Commissioner for Human Rights (OHCHR).

II. Autonomy and Independence

A. Overview of submissions

3. Submissions proposing normative elements in relation to the right to autonomy and independence painted a varied picture of the extent to which these rights are protected in national law and practice. Many submissions noted that, while the right to autonomy might not be expressly guaranteed in the constitution of many States, it was implicitly recognised in general guarantees of the right to equality or equal recognition before the law, rights to dignity or bodily integrity, rights to personal freedom and to the free development of one’s personality, or obligation to secure the happiness or welfare of all citizens. Other submissions referred to other constitutional provisions that explicitly mentioned older persons or age, including provisions which impose on the State a duty to ensure the welfare of older persons or provisions which proscribed discrimination on the basis of age (generally along with other prohibited grounds of discrimination). In other cases, the legal autonomy of older persons was described as an assumption underlying the legal system: all persons who had reached the age of majority were assumed to have full legal capacity and autonomy.

4. Many submissions also referred to laws that recognised and protected the autonomy and independence of older persons. Some of these laws were laws of general application that included protections for older persons (such as civil and commercial codes or anti-discrimination laws that included age as an impermissible ground of discrimination in areas covered by the laws); others were laws protecting the rights of older persons generally or in a number of areas, while others were specific sectoral laws in areas such as aged care or social security that included guarantees of autonomy in those sectors. Many submissions also referred to the recognition of the autonomy of older persons in the context of requirements of informed consent to medical treatment.

¹ A/AC.278/2019/1

5. A number of submissions noted that in States that had become party to the Inter-American Convention on Protecting the Human Rights of Older Persons the provisions of that treaty explicitly relating to autonomy and independence were part of the national legal order. Other submissions noted that other human rights conventions such as the International Covenant on Civil and Political Rights and the European Convention on Human Rights contained provisions that guaranteed to some extent autonomy and independence (for example, the right to respect for one's private and family life) and that these guarantees also formed the part of the domestic legal order in some States.

6. Against this background of varying constitutional and statutory guarantees of the right to autonomy and independence, examples were also provided of legislative regimes that did not adequately ensure respect for the autonomy and independence of older persons and in some cases might undermine those rights. The category of laws mentioned most often in this regard were laws permitting the limitation or overriding of the exercise of legal capacity by older persons on grounds such as imputed incapacity. In addition, a number of submissions referred to the lack of adequate legislative frameworks ensuring the legal and practical effectiveness of advance healthcare directives and continuing powers of attorney: these were important mechanisms for allowing older persons to express their will and preferences in advance. In some States these were given legal effect, while in others this was not the case and the legal framework was not well developed. Other submissions noted that, while in some States there were laws prohibiting discrimination on the basis of age, these did not always extend to some important areas of social and economic life, for example, housing services.

7. A number of submissions identified formal mechanisms for consultation with older persons and their organisations, in addition to the general procedures for involving citizens in the development of law and policy. Senior citizens councils at national regional and local level, and regular consultations – sometimes mandated by law – were referred to. While many of these standing and ad hoc consultation processes were seen as helpful, concern was also expressed that in some instances commitments to consultation were not underpinned by adequate funding and that in some cases consultations were proforma rather than actually influencing policy making.

8. Many submissions identified the different types of recourse potentially available to deal with complaints of alleged violations of the right to autonomy and independence of older persons. These included the normal civil remedies available through the judicial system for violations of the constitution or legislative guarantees, administrative remedies available through administrative courts or institutions such as Ombudspersons (including some Ombudspersons with a specific mandate in relation to age or older persons), complaints and investigative powers of national human rights institutions, informal and formal complaints procedures in areas such as health, social services and residential aged care homes. Various submissions noted that, even where there were formal protections of the autonomy and independence of older persons and formal remedies were available, in many cases these were often difficult to access, took considerable time and did not provide real and effective remedies.

9. While the most appropriate way of ensuring that autonomy is best guaranteed by law may vary due to different constitutional structures, legal traditions and legislative practices, the Open-Ended Working Group on Ageing may wish to consider whether States should be encouraged adopt an explicit general guarantee of autonomy at the constitutional level or in legislation if they do not already have such a guarantee, and also what types of procedures are most likely to provide effective redress.

B. Conceptual basis

10. The submissions manifested a significant degree of consensus on the scope of the terms of autonomy and independence, though it was noted that the relevant international documents do not provide clear and consistent definitions of each term. Some submissions noted that, while autonomy and independence were closely related concepts, there were nonetheless differences between them. Autonomy was described in many submissions as the right to have control over one's life and to make one's own decisions and to have those decisions respected (which also implies the right of older persons 'to take risks'). Independence was described in different ways, including the ability of a person to perform functions related to daily living, to be able to carry out one's decisions in practice and to be able to remain fully integrated in society and community life.² The terms self-determination and self-realisation have also been used in this context. The term independence, particularly in conjunction with autonomy, is used by some as encompassing many aspects of a right to full inclusion and participation in society.³ Some submissions viewed the concept of autonomy itself as having some of these broader dimensions, a reading also supported by the Independent Expert (autonomy has 'an individual aspect, which includes the capacity to make decisions; an economic and financial aspect, understood as self-sufficiency and the ability to generate and receive income; and a societal aspect'⁴).

11. The two terms have been linked in a number of recent binding and non-binding international instruments, including the Inter-American Convention on Protecting the Human Rights of Older Persons, the Convention on the Rights of Persons with Disabilities (as one of the 'General Principles' underpinning that convention⁵), and Council of Europe Recommendation CM/Rec (2014)2.⁶ In the Inter-American Convention, independence and

4/22

² The Independent Expert of the Human Rights Council on the enjoyment of all human rights by older persons has described the terms as follows:

'46. Autonomy and independence are mutually reinforcing and are often used interchangeably in legal instruments and frameworks. While autonomy refers to the ability to exercise freedom of choice and control over decisions affecting one's life, including with the help of someone if needed, independence means to live in the community without assistance or, at least, where the amount of help does not subject older persons to the decisions of others. In that sense, the concept of independence is broader than autonomy...' Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, A/HRC/30/43, para 46 (2015).

³ The United Nations Principles for Older Persons, adopted by the General Assembly resolution 46/91, use the term 'independence' in this broad sense, entitling older persons to access to all resources need to maintain an adequate standard of living, access to work or income-generating opportunities, the right to decide on their withdrawal from the labour force, access to appropriate educational and training programmes, the right to live in safe and adaptable environments, and to reside at home for as long as possible. Principles 1-6.

⁴ Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, A/HRC/30/43, para 44 (2015).

⁵ Article 3 of the Convention on the Rights of Persons with Disabilities provides:

'General principles

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons ...'

⁶ Recommendation CM/Rec (2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons. 'III. Autonomy and participation:

9. Older persons have the right to respect for their inherent dignity. They are entitled to lead their lives independently, in a self-determined and autonomous manner. This encompasses, inter alia, the taking of independent decisions with regard to all issues which concern them, including those regarding their property, income, finances, place of residence, health, medical treatment or care, as well as funeral arrangements. Any limitations should be proportionate to the specific situation and provided with appropriate and effective safeguards to prevent abuse and discrimination.'

autonomy are identified both as general principles⁷ and as a freestanding right, and are also referred to in provisions guaranteeing the rights of older persons receiving long-term care and the right to recreation, leisure and sports.

12. Thus the concept of autonomy itself, certainly when paired with that of independence, is not only a general statement of the right to take one's own decisions and to have them respected, but also the right to enjoy conditions that make it possible for older persons in practice to exercise that decision-making capacity, carry out their decisions and have those decisions respected, thus ensuring participation in a broad range of social activities according to the will and preferences of the person concerned.

C. Specific issues

Recognition of legal capacity and its exercise

13. Many submissions raised the issue of the right to autonomy in the context of the recognition of legal capacity and guarantees relating to its exercise and respect for decisions taken in the exercise of that capacity. While only a part of the topic of legal capacity, the institutions of guardianship or curatorship and the availability and effectiveness of advance health directives and continuing or enduring powers of attorney were raised by a number of submissions.

14. In relation to the possession and exercise of legal capacity by older persons, various submissions referred to the Convention on the Rights of Persons with Disabilities which also addresses this issue in relation to persons with disabilities. Similar, more briefly expressed statements of the right to legal recognition of a person before the law appear in other human rights treaties, including the International Covenant on Civil and Political Rights (Article 16), the Convention on the Elimination of All Forms of Discrimination against Women (Article 15) and regional human rights treaties.

15. The provisions of the Convention on the Rights of Persons with Disabilities relating to legal capacity have been described as representing a shift from a framework of 'substituted decision-making' for persons with disabilities to a one of 'supported decision-making'. As of 15 March 2019, there were 177 States parties to the Convention on the Rights of Persons with Disabilities. While many States have undertaken reviews of their laws relating to the legal capacity of persons with disabilities, in particular their guardianship regimes, there are other States in which this has not taken place or are still underway. The Committee on the Rights of Persons with Disabilities has articulated its understanding of the relevant provision of that Convention in this regard in its *General comment No 1*.⁸ While the gist of the Committee's view of the Convention is broadly accepted, some States and commentators have expressed concerns about certain aspects of it.

16. The categories of older persons and persons with disabilities are not the same: older persons who are not living with disability will not fall within the scope of the Convention on the Rights of Persons with Disabilities so far as the recognition of their legal capacity and its exercise are concerned. Nonetheless, there is overlap and the issues relating to legal capacity

5/22

⁷ Inter-American Convention, article 3(c): 'General principles that apply to the Convention: ... (c) The dignity, independence, proactivity, and autonomy of older persons ...'.

⁸ Committee on the Rights of Persons with Disabilities, *General comment No 1: Article 12: Equal recognition before the law*, CRPD/C/GC/1 (2014).

and its exercise are similar. It is desirable that any international standard that might be developed be consistent with and not fall below the standards developed in and under the Convention on the Rights of Persons with Disabilities. The Open-Ended Working Group may wish to deliberate on how best to ensure that any normative standard that may be developed could build on and if appropriate clarify or strengthen the guarantees in the Convention on the Rights of Persons with Disabilities as interpreted by the Committee on the Rights of Persons with Disabilities and States parties to that treaty.

Advance exercises of legal capacity

17. A number of submissions referred to the need to have in place an effective legal regime which recognised the expressions of the wishes of an older person made in contemplation of a loss of relevant capacity. These include advance healthcare directives and continuing or enduring powers of attorney. While these have legal effect in some States, submissions showed that in others this was not the case – either because there was no legislative provision for the use of such documents or because the position as to their legal effectiveness was not clear. The Open-Ended Working Group may wish to consider how further instruments and measures might encourage and provide guidance to States in ensuring that the exercise in an advance by older persons in the form of advance health directives, or continuing powers of attorney or similar instruments to ensure that the exercise by older persons of their autonomy is legally and practically respected.

Equality and non-discrimination

18. As number of submissions underlined the importance of recognising that older persons are not a homogeneous group and that it was necessary to take into account the importance of intersectional discrimination in the enjoyment of the rights to autonomy and independence.

Other issues

19. Some submissions raised other matters. One submission noted that the sexuality of older persons and their right to have intimate relationships were frequently a taboo subject, yet these are accepted under international human rights law as an important aspect of various rights including the right to private and family life. Other submissions raised the issue of participation by older citizens through voting and the barriers to older persons' full participation (for example, the lack of postal votes or difficulties in obtaining transport to polling stations).

D. Definition

20. One issue that is raised by existing treaties and some submissions is how autonomy and independence should be recognised by and included in any normative standard developed, in particular whether they should be included as a general principle, a freestanding substantive right, included in specific rights, included in a preamble, or some combination of these options. As noted earlier, autonomy and independence are included as a general principle in the Convention on the Rights of Persons with Disabilities and specific references are made to the concept in individual articles (for example, the right to independent living). On the other hand, the Inter-American Convention on Protecting the Rights of Older Persons includes autonomy

and independence as underlying principles, a freestanding right, as well as including references to it in specific provisions.⁹

21. The Open-Ended Working Group may wish to consider whether it is appropriate to include autonomy and independence in any normative outcome as an overarching principle, as a freestanding right, or as an aspect of a number of specific rights, or some combination of these.

22. The various understandings and formulations of autonomy and independence have been described above. Statements of the right to autonomy and independence proposed in submissions set out in the statement of the right the various elements that were identified as core elements of autonomy and independence. Neither the Inter-American Convention nor the Convention on the Rights of Persons with Disabilities contain a specific definition of autonomy or independence. This is in contrast to a number of domestic laws which define one or both terms. The Open-Ended Working Group may wish to consider whether it would be preferable to include a separate definition of either autonomy or independence in any normative outcome or whether a statement or affirmation of the right indicating the core elements of the right would be a more appropriate way of articulating the right.

E. Affirmation of the right – possible normative elements

23. Some submissions proposed that autonomy and independence be included as an explicit general principle underlying any international standard that may be developed, as well as being formulated as a specific right. A number of possible formulations of right to autonomy and independence were proposed in submissions. Some of those restricted themselves to a general statement of the right, while others included in their statement of the right elements relating to specific rights, for example to right to decide on one's own living arrangements or the right to enjoy and exercise legal capacity on the basis of equality with others.

24. Normative elements proposed for inclusion in a statement of the right are that older persons have the right to autonomy and independence that includes:

- (a) the right to personal autonomy and independence over all aspects of their lives on an equal basis with others;
- (b) the right to enjoy and exercise legal capacity, to make their own decisions, to determine their own life plans and to lead autonomous and independent lives, in accordance with their will and preferences, on an equal basis with others;
- (c) the right to have their decisions respected;
- (d) the right to support to enable them to exercise their right to autonomy and independence, including the right to designate one or more trusted persons to assist them to make decisions based on their instructions, will and preferences;
- (e) the right to choose where and with whom to live (including the right to live independently in the community on an equal basis with others) without being obliged to live in any particular living arrangement and to have their right to autonomy and independence respected in also shared residential settings;
- (f) the right to support to enable their independent living and full inclusion in the community, including any care, personal assistance and support necessary to enable

⁹ See also ECLAC, *Challenges to the autonomy and interdependent rights of older persons*, Fourth Intergovernmental Conference on Ageing and the Rights of Older Persons in Latin America and the Caribbean, held in Asunción, on 27-30 June 2017, [LC/CRE.4/3/Rev.1](https://repositorio.cepal.org/handle/11362/41643) (2018), <https://repositorio.cepal.org/handle/11362/41643>

them to have control and autonomy over the tasks and activities that make up their daily lives as well as access to community services and facilities that enable them to participate in community and public life; and

- (g) the right to full, effective and meaningful participation in all aspects of life, including participation in family, social, cultural, economic, public and political and in educational and training activities.

Legal capacity

25. Various submissions also put forward proposed normative content in relation to the right to equal recognition as a person before the law and the associated rights to possess and to exercise legal capacity. These elements included affirmations that older persons:

- (a) are entitled to equal recognition as persons before the law and as rightsholders;
- (b) enjoy legal capacity and the right to exercise that capacity on an equal basis with others in all aspects of life;
- (c) have the right to support to enable them to exercise their legal capacity, including the right to designate one or more trusted persons to assist them to make decisions based on their instructions, will and preferences and the right to make legally binding documents to express their will and preferences in advance;
- (d) have the right to make legally binding documents to express their will and preferences in advance;
- (e) 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;
- (f) have the right to safeguards to enable them to exercise their legal capacity; and
- (g) have the right to an accessible and effective complaints mechanism and appropriate remedy in cases in which an older person's right to enjoy and exercise legal capacity has been violated.

F. State obligations – possible normative elements

26. Submissions also put forward proposed normative elements relating to the obligations of States under any international standard that may be developed. These generally corresponded to the specific elements of the positive statement of the rights. These included proposed normative elements that States should take necessary, appropriate and effective measures:

- (a) to ensure older persons have access to appropriate and effective services and supports including the right to legal counsel (which are free of conflict of interest and undue influence and are tailored to the older person's circumstances) to enable them to exercise their right to autonomy and independence, and to respect their will and preferences in accordance with international human rights law;
- (b) to ensure mechanisms designed to enable the exercise of older persons' right to autonomy and independence recognise their right to legal capacity and to exercise it on an equal basis with others in all aspects of life;
- (c) to ensure the full, effective and meaningful participation of older persons in family, social, cultural, economic, public and political life and educational and training activities;
- (d) to ensure that communities and environments are age-sensitive and age-friendly;

- (e) to ensure 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;
- (f) to ensure 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 any cultural, spiritual, professional and environmental challenges of these facilities;
- (g) to ensure the ability of older persons to execute legally binding advance directives through which they can express their will and preferences with free, informed, genuine and irrevocable consent;
- (h) to ensure that older people are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law; and
- (i) to ensure that older persons have access to an accessible and effective complaints mechanism and appropriate remedy in cases in which an older person's right to enjoy and exercise their autonomy and independence has been violated.

Legal capacity

27. In relation to legal capacity and its exercise, a number of submissions proposed normative elements that were derived in large part from the Convention on the Rights of Persons with Disabilities and the practice under that treaty. They included normative elements proposing that States should:

- (a) ensure that national law and practice recognises the right of older persons to enjoy and exercise legal capacity;
- (b) ensure that guardianship and other laws are consistent with the assumption of legal capacity and embody the concept of supported decision-making where that is necessary to ensure older persons can exercise their legal capacity and autonomy;
- (c) ensure older persons have access to services to support the exercise of their legal capacity, including access to trusted support persons, peer support, advocacy support and assistance with communications, among other supports;
- (d) ensure that any measures relating to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law and that such safeguards ensure that the measures reflect the rights will and preferences of the person, are free of conflict of interest or undue influence and are proportionate and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial court or other appropriate body; and
- (e) ensure that older persons have access to an accessible and effective complaints mechanism and appropriate remedy in cases in which an older person's right to enjoy and exercise legal capacity has been violated.

28. The Open-Ended Working Group may wish to consider whether any international standard that may be developed should include some or all of the elements set out above as part of a right to autonomy and independence or whether it is appropriate to include them in such a standard in some other way.

III. Long-Term Care

A. Relationship between the right to long-term care and the right to palliative care

29. The Guiding Questions dealt with the right to long-term care and the right to palliative care as related rights, as did the Open-Ended Working Group in its substantive discussions at its ninth session. While there is some overlap in the scope of operation of those rights, the two rights are not identical in scope and operation, and many submissions proposed a separate explicit statement of a right to palliative care grounded in the right to health (among other rights). This working document has adopted that approach. The Open-Ended Working Group may wish to consider how best to reflect the interrelatedness of and differences between the right to long-term care and the right to palliative care, in particular the need for a specific statement of each right and the relationship of each to the right to health and other rights.

B. Overview of submissions

30. The submissions evinced broad agreement that long-term care included the provision of care and support in many contexts (for example, at home, in the community, in residential homes such as assisted living or nursing homes) and that its primary goal should be to ensure the enjoyment by older persons of their right to autonomy and independence by providing them with the support that they needed to carry out their daily lives in accordance with their will and preferences. It was suggested that referring to the right to ‘long-term care *and support*’ would better capture the underlying goals of the right; the Open-Ended Working Group may wish to use this terminology in its future discussion of the right.

31. The submissions showed that there is considerable variety in the ways in which long-term care services are provided: they vary in how they are legally guaranteed and regulated, whether they are underpinned by a human rights framework, and whether they are adequately funded and appropriately monitored. In some States the process of providing or supporting the provision of long-term care services is still in its early stages, while others have a more highly developed system of long-term care. In some countries long-term services were provided by the State, while in others this was done by the private sector, while in others both public and private actors were involved in providing such services. However, most submissions indicated that there continued to be challenges in meeting the current and projected demand for high-quality and affordable long-term care and support services in their communities. Many submissions identified general and sector- or institution-specific procedures for raising concerns about violation of the right to access long-term care services, though there were few indications of the extent to which these were used and had provided effective and timely redress.

32. Various submissions noted that in some countries there was a strong cultural expectation that long-term care would be provided by a person’s family (although these arrangements were probably not as common as previously); in some contexts, the development of residential aged care homes would be seen by some as ostracising or rejecting the older generation. Some submissions also noted that older persons might wish to exercise their own autonomy and independence and prefer not to live with family members. Some submissions referred to the legislation in some States that conferred on older persons the legal right to seek financial support from children, grandchildren or other close relatives if they were otherwise

unable to survive. UN Women noted the gendered impact of relying on family members to provide unpaid care services: these caregivers were overwhelmingly women and as a result of providing such care their ability to participate in paid work was limited and not otherwise recognised or compensated, with consequent disadvantages for them so far as economic security in their own older age was concerned.¹⁰ UN Women also drew attention to issues relating to the need to recognise and support paid and unpaid care providers to decrease their marginalisation from policymaking and to enhance the status and reduce the exploitation of domestic workers or those working in care.

33. Some submissions urged the adoption of innovative approaches to long-term care, including the development of and support for inter-generational community and cooperative living arrangements. Other submissions referred to the challenges that arise in institutional contexts, in particular the danger of disempowering older persons who are resident in these institutions and the need to adopt a culture that supports the exercise of autonomy and independence by residents.

34. Many submissions referred to the following as critical elements for the effective realisation of the right: the existence of strong, rights-based legislative and policy frameworks for the provision of long-term care and support in different contexts; the need for coordination among agencies or different levels of government responsible for funding, development of policy and implementation of programmes; the need for clearly articulated quality standards for care, independent oversight procedures and effective informal and formal complaint procedures; the need to develop sustainable financing for the provision of long-term care and support as well as the need to recognise the economic as well as personal and social benefits of ensuring the enjoyment of this right; and the need to ensure appropriate training for those working in the field.

C. Conceptual basis

35. Many submissions highlighted the importance to the right to long-term care of the right to the highest attainable standard of health guaranteed in Article 25 of the Universal Declaration of Human Rights and Article 12 of the International Covenant on Economic, Social and Cultural Rights, among other international instruments. The right to social security was another right that was seen as overlapping with and facilitative of the enjoyment of the right to long-term care. Other submissions emphasised that the right to long-term care needs to be seen as part of a comprehensive and coherent framework for the promotion and protection of the rights of older persons. Other submissions mentioned in particular that the right also encompassed important dimensions of the right to autonomy and independence, including the right of a person to choose where and with whom they lived and the right to live independently in the community, rights guaranteeing participation in economic, social, political and cultural life of the community, freedom of association and right to respect for one's private and family life, among other rights. A number of submissions pointed to constitutional provisions that obliged the State and society to ensure the health and welfare of older persons as the source of legal obligation at the national level that underpinned this right.

¹⁰ See also UN Women, *Long-term care for older people: a new global gender priority*, Policy Paper No 9, 2017, www.unwomen.org/en/digital-library/publications/2017/12/long-term-care-for-older-people.

D. Definition

36. A number of submissions referred to national definitions of the concept of long-term care (and support) and the different types of long-term care and support services that were available, while other submissions noted the absence of any formal national definition. Most of the submissions which considered the question of the definition or material scope of favoured a broad definition of ‘long-term care’ which would include social, healthcare and support services provided to older persons in all public and private settings, including at home, community-based services day-care centres, residential institutions, hospitals, hospices, prisons or other settings and which are provided by both formal and informal caregivers or support providers (including volunteers). The adoption of a broad definition may have implications for the nature and extent of legislation regulation to ensure enjoyment of the right and the extent and forms of State support and financing required to ensure enjoyment of the right.

37. The Inter-American Convention on Protecting the Human Rights of Older Persons initially adopts a narrower definition of the scope of long-term care services in its Article 2 definition of ‘older person receiving long-term care services’, which focuses on persons residing in regulated establishments which provide comprehensive social and healthcare services.¹¹ However, the statement of the right to long-term care in Article 12 of the Inter-American Convention has a broader scope of operation and explicitly affirms the right to a comprehensive system of care that ‘promotes the older persons to stay in their own home and maintain their independence and autonomy should they so decide.’ These provisions of the Convention have also been incorporated into domestic law by some States parties to that Convention.

38. The Open-Ended Working may wish to consider the desirability of adopting a broad definition of long-term care and support which includes a variety of social, healthcare and other support services provided to older persons in their homes, in the community, in residential institutions or in other contexts, with the goal of supporting older persons’ right to autonomy, independence, quality of life and participating in the community.

E. Affirmation of the right to long-term care and support

39. Many submissions made detailed suggestions of normative elements that might be included in a statement of the right and associated obligations of the State. The normative elements suggested for inclusion in a statement of the right included that the affirmation that older persons have the right to long-term 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 that are:

- (a) affordable;
- (b) accessible;
- (c) acceptable;
- (d) appropriate;
- (e) integrated;

¹¹ “‘Older person receiving long-term care services’: One who resides temporarily or permanently in a regulated, public, private or mixed establishment, which provides quality comprehensive social and health care services, including long-term facilities for older persons with moderate or severe dependency, who cannot receive care in their home.’

- (f) of high quality;
- (g) timely;
- (h) holistic;
- (i) adapted to their individual needs; and that
- (j) promote and protect their well-being;
- (k) maintain their dignity, autonomy and independence and enable them to fully participate in society; and
- (l) without discrimination of any kind.

40. Further it was proposed that as part of the right to long-term care and support older persons have:

- (a) the right to information about all aspects of their care and support needs and services;
- (b) the right to choice and control over their care and support services, and to support to exercise this right;
- (c) the right to the care and support services they require, independent of, and unrelated to, the income of their family members; and
- (d) the right to safeguards to enable them to exercise their right to care and support.

F. State obligations – possible normative elements

41. Various submissions also proposed normative content for obligations that would apply to States under any international standard that may be developed. These elements of obligation draw on the concepts and specific elements of the right to long-term care noted above, on existing binding and non-binding instruments dealing with the rights of older persons general human rights instruments and the right of older persons, and on the positive and negative experiences at the national level presented in the submissions. Most, though not all, of the elements set out below were proposed in more than one submission.

42. The proposed elements would oblige States to take all appropriate measures, without discrimination of any kind:

General

- (a) to establish an appropriate legal and policy framework that guarantees the right of older persons to access to all appropriate forms of long-term care and support;
- (b) to develop and implement policies to integrate long-term care policies with the national health, and social welfare and support systems and to ensure adequate public and private financing of care and support services;
- (c) to make available and accessible to older persons an affordable range of care and support services, including in-home, residential and other community services including personal assistance and assistive technologies, to ensure older persons' enjoyment of the right to choose where they live and with whom on an equal basis with others, and independent of, and unrelated to, the income of financial resources of their family members;
- (d) 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.

- (e) to ensure older persons have choice and control over care and support services which are adapted to their individual needs and preferences;
- (f) to ensure older persons have access to information about their health status so their decisions can be free, prior and informed and to ensure the confidentiality of information is guaranteed;
- (g) 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 or commencement of the support service;
- (h) 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;
- (i) 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;
- (j) 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;
- (k) to ensure public awareness to safeguard the rights of older persons receiving care and support in any setting;

Establishment, monitoring and enforcement of standards/training

- (l) to establish, 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;
- (m) to ensure quality standards for care and support services are based on human rights principles;
- (n) to ensure that measures to ensure the safety of older persons in care and support do not compromise the right of older persons to autonomy and independence;
- (o) to ensure that the right of older persons to personal integrity and to freedom from torture, inhuman or degrading treatment, including the right to be free from all forms of seclusion and restraint (including chemical restraints) is respected;
- (p) 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;
- (q) 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;
- (r) 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; and
- (s) to generate and publicise data about the effects of long-term care on women, including the working conditions and well-being of paid and unpaid care providers.

Participation and inclusion in the community

- (t) 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;
- (u) 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;
- (v) to ensure older persons have the opportunity to participate in the design, development and evaluation of assistive technologies and devices; and
- (w) to ensure older persons have the opportunity to participate in policy decision-making process on all forms of care and support, including assistive technologies.

Redress

- (x) 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; and
- (y) 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.

43. The Open-Ended Working Group may wish to consider whether any international standard that might be developed should contain some or all of the elements set out above as part of a right to long-term care and support or whether it is appropriate to include them in any such standard in some other way.

IV. Palliative Care**A. Overview of submissions**

44. The submissions proposing normative elements in relation to the right to palliative care show that the situation with regard to access to palliative care services varies widely among States, although almost every submission indicated that there were deficiencies in ensuring access to such services for all without discrimination. Those limitations included a lack of legislative or policy frameworks, failure to integrate palliative care services into existing health policy and insurance systems, insufficient funding and resources generally and within public health systems in particular, an insufficient number of trained physicians and other health professionals to provide palliative care services, restriction of palliative care services to a limited number of diseases while not including others that were appropriate for palliative care services, inadequate access to medicines required for pain relief, unequal access to palliative care services on the basis of economic status, residence in a rural area or on other bases. Submissions also provided information about the various avenues for seeking recourse against a violation of the right, though without detailed information on whether these avenues had been used in such cases and had provided effective remedies.

45. Many examples of good practice in legislation, policy and programmes were provided as the basis for possible normative elements in any international standard that might be developed; the inadequacies identified also indicated that remedying such inadequacies were also seen as necessary to realise fully the right to palliative care and as relevant to the

obligations that might be included in any such standard. The followings section draws on those elements.

B. Conceptual basis

46. Many submissions grounded the right to palliative care primarily in the right to the enjoyment of the highest attainable standard of health guaranteed in Article 25 of the Universal Declaration of Human Rights and Article 12 of the International Covenant on Economic, Social and Cultural Rights among other international instruments. Other submissions noted that the right is also grounded in the rights to life, dignity and autonomy. A number of submissions pointed out that a failure to provide palliative care and to ensure a person was not left to experience preventable suffering could also involve a violation of the right not to be subjected to torture or cruel, inhuman or degrading treatment or punishment guaranteed by Article 5 of the Universal Declaration of Human Rights, Article 7 of the International Covenant on Civil and Political Rights, the Convention against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment or Punishment and other international instruments.

47. The Open-Ended Working Group may wish to consider how best to reflect these various aspects of the right to palliative care in the formulation of these different rights which might appear in separate articles in any international standard that may be developed.

C. Definition

48. Many submissions referred with approval to the definition of palliative care adopted by the World Health Organisation (WHO)¹². Many other submissions endorsed a holistic approach to palliative care that was consistent with and drew on the WHO approach. Reference was also made to other definitions that build on the WHO definition, for example the consensus definition of the International Association for Palliative and Hospice Care (IAHPC). The IAHPC argues that palliative care should not be limited to problems associated with life-threatening illnesses but should also ‘extend to the needs of patients with severe, chronic and complex conditions’.¹³ Further submissions referred to other policies and statements on palliative care, including non-binding recommendations of the Council of Europe and statements by professional medical associations.¹⁴

49. In addition, a number of submissions referred to the definition of palliative care¹⁵ and statement of the right to palliative care that appears in the Inter-American Convention on Protecting the Human Rights of Older Persons. This definition and the other provisions of the Convention have also been incorporated into domestic law by some States parties to that Convention: in those States it forms part of the legal framework regulating the right to palliative care, in some cases with complementary national legislative frameworks.

¹² <https://www.who.int/cancer/palliative/definition/en/>.

¹³ <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/>

¹⁴ See, e.g., World Medical Association Declaration of Venice on Terminal Illness and world Medical Association Declaration on End-of-Life Medical Care: WMA, pp 2-3.

¹⁵ “‘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 2, Inter-American Convention on Protecting the Human Rights of Older Persons.

50. In some States there is no legislative definition of palliative care or legislative conferral of a right to access palliative care services. In other States there are definitions contained in national laws, some of which also guarantee an explicit legal right to access palliative care. Sometimes the right to access palliative care is not guaranteed explicitly in the constitution or in legislation but has been derived from constitutional rights to life or dignity, from the right to health¹⁶ or from a constitutional mandate to guarantee the well-being of older persons. In other cases, there is no explicit or implicit legal recognition of a right to palliative care, although this may be provided for under health policies and programmes.

51. Where access to palliative care is available as a result of legal guarantees or as a matter of practice, eligibility for such care may not extend to all older persons who are suffering from a condition that involves suffering severe pain. In some cases, palliative care is available only to patients suffering from terminal cancer; in other cases, it is available for those suffering from tuberculosis or AIDS, while in still others it is available in to patients who are suffering from other terminal, chronic diseases and degenerative and irreversible diseases.

52. Equally, in some States palliative care may only be available to those who are critically ill and dying, while in others relief from severe pain may be available from the time of diagnosis as needed. Some submissions noted that palliative care should be available at any stage of illness and that information about palliative care options should be made available from early in a person's illness so that they and their families can plan the steps to be taken before the illness or disease has advanced to a critical stage.

53. The Open-Ended Working Group may wish to examine the WHO approach and other formulations of the nature and extent of the right to palliative care in deciding on an appropriate formulation of the right and its coverage, and whether developments since the adoption of the WHO definition in 2002 require adjustment to that approach and definition. The Open-Ended Working Group may also wish to consider the question of the stage of illness at which palliative care should be made available to older persons, and whether restricting the availability of palliative care services to some illnesses but not extending them to other serious illnesses is an appropriate way of fully ensuring the rights to health and dignity and other rights that underpin the specific right to palliative care.

D. The placement of a right to palliative care in any normative standard: freestanding or integrated in other rights

54. Many submissions supported the inclusion of a specific and self-contained right to palliative care in any international standard that may be developed. A number also suggested possible wording for both a brief affirmation of the right to palliative care and a detailed list of the measures that States would be obliged to take to ensure full enjoyment of the right. Many of these affirmations of the right endorsed the availability, accessibility, appropriateness and affordability framework.

55. The Inter-American Convention on Protecting the Human Rights of Older Persons includes references to palliative care in a number of articles: Article 6 (obligations of States Parties to take steps to ensure that public and private institutions offer older persons 'access without discrimination to comprehensive care, including palliative care ...'); Article 11 (requiring States Parties to establish a procedure permitting older persons to 'expressly

¹⁶ See, e.g., Dominican Republic, p 10; Nigeria [NHRI?], p 8; Ecuador, LTCPC, p 1.

indicate in advance their will and instructions with regard to healthcare interventions, including palliative care'), Article 12 (obligation to ensure persons receiving long-term care also have palliative care services available to them); and Article 19 (obligation to design and implement comprehensive-care oriented public health policies that include palliative care, to promote and strengthen research and training in the relevant fields, and ensure medicines needed for palliative care are available).

56. The Open-Ended Working Group may wish to consider how best to include the various elements of State obligation in any international standard that may be developed, in particular whether a freestanding and largely self-contained right to palliative care is the most appropriate option, whether the right and consequent obligations should be included as part of a general right to health, or whether various aspects of a State's obligations should appear in different articles of any such standard.

E. Affirmation of the right to palliative care

57. As already noted, many submissions proposed the inclusion of a separate right to palliative care, embodying a guarantee that all older persons will be provided with services and support that will help them achieve a dignified and pain-free death with choice over how they are cared for in the late stages of their life (as well as in other times of life when they are suffering from severe pain as a result of illness). The elements set out in the next paragraph were proposed for inclusion in any formulation of the right to palliative care.

58. Older persons have the right to palliative care that is:

- (a) timely (available from the time of diagnosis, not just at the terminal stages of an illness);
- (b) of high quality;
- (c) comprehensive (in the illnesses covered);
- (d) holistic (catering to all aspects of the person's well-being and their relationships);
- (e) accessible;
- (f) available in all settings (including at home, in the community, in residential settings);
- (g) affordable;
- (h) provided in a manner consistent with the needs, will and preferences of the person;
- (i) respectful of the right of the person to give and withdraw consent at any time; and
- (j) without discrimination of any kind.

F. State obligations – possible normative elements

59. Various submissions also proposed normative content for obligations that would apply to States under any international standard that may be developed. These elements of obligation draw on the concepts and specific elements of (the right to) palliative care noted above, on existing binding and non-binding instruments dealing with the rights of older persons including the right to palliative care, and general human rights instruments and the right of older persons, and on the positive and negative experiences at the national level presented in the submissions. Most, though not all, of the elements set out below were proposed in more than one submission.

60. The proposed elements would oblige States to take all appropriate measures, without discrimination of any kind:

- (a) to ensure that the right of older persons to palliative care is defined and guaranteed in national laws and policies;
- (b) to ensure that the right of older persons to access palliative care services is integrated into public health and social care policies and systems and health insurance plans including care and support services for older persons;
- (c) to ensure that older persons are not subjected to torture or to cruel inhuman or degrading treatment as a result of failure by public or private actors to adequately treat pain and other symptoms;
- (d) to ensure the availability, accessibility, affordability and acceptability of palliative care services in all settings to older persons, including at home, in the community, in residential settings, in hospices, in hospitals and in prisons or other institutions in accordance with their needs, will and preferences;
- (e) to ensure that older persons have timely access to information about all aspects of their health and palliative care options so they can express the free, prior and ongoing consent to palliative care treatment and other healthcare and social matters;
- (f) to allocate regular and adequate funding as part of national health budgets to enable the implementation of evidence-based palliative care across care and support services;
- (g) 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 and in particular--
 - i. to ensure narcotic drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering,
 - ii. to review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes, and to remove regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications, and
 - iii. to ensure measures are in place to safeguard against the misuse of narcotic and psychotropic drugs and other medications;
- (h) to ensure that the decisions of older persons in relation to the nature and location of any palliative care services they receive or decide not to receive or opt out of at any time are respected;
- (i) to ensure that older persons have access to a range of supports to exercise their legal capacity where necessary, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences;
- (j) to establish procedures by which older persons may prepare legally binding documents such as advance directives and living wills 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 where palliative care services are provided, and timely information of any changes in the national legislation that may impact the advanced directives and enable a periodic revision of the personal directives;

- (k) to ensure all care and support service providers, including professional and informal providers, receive education, training and supervision regarding the delivery of and access of older people to palliative care.
- (l) to ensure minimum standards in the provision of palliative care in care and support services, across all settings, including by facilitating guidance on the implementation of high-quality palliative care.
- (m) to regulate and monitor of compliance of all palliative care providers with professional obligations and standards
- (n) to ensure the participation of older persons or representative organisations of older persons in the research, design, development and monitoring of palliative care services;
- (o) to ensure access to support for family members and others close to the older person, including bereavement support;
- (p) to ensure that health professionals receive adequate training in relation to the delivery of palliative care services as part of basic medical education as well as in advanced specialist education and that sufficient numbers of healthcare professionals are trained to meet the needs for palliative care services;
- (q) to ensure the adequate and appropriate training of health, social and spiritual care and support providers, including volunteers, receive education, training and supervision regarding the delivery of and access of older people to palliative care;
- (r) to establish adequate and accessible judicial and non-judicial mechanisms, including where appropriate national human rights institutions or Ombudsman procedures or sectoral complaints procedures, that will provide for prompt and effective investigation of any complaints of violation of the right to palliative care and related rights by public or private actors, provide adequate redress and reparation to complainants, and ensure appropriate penalties for those who have violated such rights.

61. The Open-Ended Working Group may wish to consider whether the elements set out in the preceding paragraph are appropriate for inclusion in any possible future standard, and whether there are additional elements that should be included.

Other issues

62. *The right to palliative care in situations of humanitarian crisis:* One important and complex issue raised by the Office of the United Nations High Commissioner for Refugees (UNHCR) is the need to consider the implementation of the right to palliative care in emergency situations, including situations of forced displacement. UNHCR draws attention to the fact that the medical conditions may be exacerbated by forced displacement and that additional barriers to accessing health services including palliative care arise in such circumstances. UNHCR recommends that international standards take into account existing guidelines and standards on humanitarian contexts and be guided by existing frameworks for refugee response.

63. Article 11 of the Convention on the Rights of Persons with Disabilities obliges States parties to take special measures to take all necessary measures to protect the rights of persons with disabilities 'in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.'

64. The Open-Ended Working Group may wish to consider how best to formulate normative element that would address the need for States to ensure that older person in situations of risk, including armed conflict, humanitarian emergencies and natural disasters have access to appropriate health services including palliative care. More generally the Open-Ended Working Group may wish to consider whether a provision along the lines of Article 11 of the Convention on the Rights of Persons with Disabilities should be included in any international standard on the human rights of older persons that may be developed.

65. *Devolution of responsibility to sub-national or regional authorities:* A number of submissions referred to the division or devolution of responsibility in relation to long-term care and palliative care to sub-national national units such as provinces or regional authorities. In some cases this was the result of constitutional allocations of responsibilities, in other cases the result of practice. The issues to which such arrangements gave rise were whether the minimum level of enjoyment of the rights was attained in all regions and whether there were variations in the enjoyment of those rights that might be discriminatory.

66. While these issues were raised in the context of the rights to long-term care and palliative care, they are of general relevance to a State's implementation of any obligations it may assume under any international standard that may be developed; indeed, these have been addressed under existing treaty law and practice and the international law of State responsibility. The Open-Ended Working Group may nonetheless wish to consider how best to ensure the implementation of any obligations in relation to older persons is consistent across a State in which there is a formal division of responsibilities over such matters.

V. Conclusion

67. The material included in this working document has shown that the rights to autonomy and independence and the rights to long-term care and palliative care of older persons are complex and interrelated with many other rights. Nevertheless, the submissions made to this session of the Open-Ended Working Group as well as the substantive inputs provided to the ninth session have shown that there is a good deal of agreement on the underlying values and objectives that these rights embody, even as there are diverse opinions about the best ways to realise their full enjoyment.

68. The normative elements set out above which are drawn from the submissions are wide-ranging and numerous, and there is some overlap in their formulation, both within and between rights, as well as with the rights considered at the ninth session. How this should be addressed in order to reduce overlap and produce a shorter though no less comprehensive text is a matter that the Open-Ended Working Group may wish to consider at its working sessions.

Possible consideration of general normative elements

69. This working document has focused on the normative elements put forward in submissions made to the tenth session of the Open-Ended Working Group. As noted at the beginning of this document, the normative elements put forward in the submissions to the tenth session included general normative content that is relevant not only to the specific right being considered but could also be of relevance to the other rights that may be included in a possible international standard. For example, a number of submissions referred to the obligation of the State to take all appropriate measures to ensure that private actors respect an individual's right to autonomy, an obligation that may apply to most or even all rights, not just to the right of

autonomy. Normative content that might be of relevant to the formulation of a general right to redress for violation of a right has been put forward in relation to the each of the rights on which the Open-Ended Working Group has invited the submission of normative content. This material may prove useful in the elaboration of any international standard, as the general normative elements are likely to influence the content of provisions setting out the scope, underlying principles, definitions, and general obligations of States under such a standard.