

**SUBMISSION ON THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING**

This submission sets out analysis by the Equality and Human Rights Commission[[1]](#endnote-1) on the normative elements that could form part of potential international standards on older people’s rights to **autonomy and independence** and **palliative and** **long-term care**. This is an early contribution to discussions, and is likely to be refined based on further discussions with civil society organisations and other stakeholders, particularly older people themselves.

The development of the normative framework should recognise that older people are not a homogeneous group, and must be sensitive to intersectionality and the range of lived experience of older people. In addition, the full range of rights for older people should be considered as indivisible, interdependent and interrelated.[[2]](#endnote-2) [[3]](#endnote-3)

While a number of existing international and regional human rights treaties help to illuminate key normative elements of the rights of older people, analysis has revealed gaps in protection of older people’s rights.[[4]](#endnote-4) This submission sets out relevant provisions within the current international legal framework, highlights key gaps, and suggests potential normative elements that would bridge these gaps and could empower older people to claim their rights.

1. **AUTONOMY AND INDEPENDENCE**

**Current framework:**

1. *Legal recognition and autonomy in decision-making:* The right to equal recognition before the law is enshrined in Article 16 of the International Covenant on Civil and Political Rights (ICCPR). Article 12 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) protects this same right in relation to disabled people, and requires support for exercising legal capacity in ‘all aspects of life’ including property and financial affairs, as well as respect for ‘the rights, will and preferences of the person’. Interpretation of UNCRPD Article 12 has emphasised the importance of moving from ‘the substitute decision-making paradigm to one that is based on supported decision-making’.[[5]](#endnote-5) At regional level, Article 8 of the European Convention on Human Rights (ECHR) encompasses the right to respect for personal autonomy and dignity, including being involved in decisions about one’s own life.[[6]](#endnote-6) Article 7 of the Inter-American Convention on Protecting the Human Rights of Older Persons includes the right to make decisions and determine one’s own life plans. The UNCRPD also requires that disabled people are meaningfully involved in decisions that affect their lives.[[7]](#endnote-7)
2. *Choice and control over living arrangements:* UNCRPD Article 19 on living independently in the community protects this right in relation to disabled people. Article 19(a) protects disabled people’s right to ‘choose their place of residence and where and with whom they live on an equal basis with others’ and to not be ‘obliged to live in a particular living arrangement’. This has been interpreted to include ‘all aspects of a person’s living arrangement’, and to clarify that choice is only meaningful with sufficient options and information about options.[[8]](#endnote-8) In addition, UNCRPD Article 19 and ECHR Article 8 should be interpreted in a way that enables individuals to take risks, within reason, when deciding on their living arrangements and support.
3. *Access to support services, general services and an inclusive environment:* UNCRPD Article 19(b) requires ‘access to a range of in-home, residential and other community support services’, across a range of areas of life,[[9]](#endnote-9) to enable full inclusion within the community. UNCRPD Article 19(c) requires that services and facilities available to the general population are equally available to disabled people and respond to their needs.[[10]](#endnote-10) Interpretation has clarified that general services should be designed to be ‘universally accessible, acceptable and adaptable’.[[11]](#endnote-11) UNCRPD Article 9 sets out detailed requirements for accessible services and facilities.[[12]](#endnote-12) In addition, UNCRPD Article 5(3) requires that ‘reasonable accommodation’ is provided in order to promote equality.[[13]](#endnote-13)
4. *Liberty, security and personal integrity:* ICCPR Article 9 protects the right to liberty and security of the person, including freedom from arbitrary deprivation of liberty. UNCRPD Article 14 enshrines this same right in relation to disabled people, and UNCRPD Article 17 protects the mental and physical integrity of disabled people. ICCPR Article 10 provides that ‘all persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person’.[[14]](#endnote-14) ECHR Article 5 protects liberty and security of the person in similar terms, and ECHR Article 8 has been interpreted to include the right to respect for personal dignity and the right to control one’s own body.[[15]](#endnote-15)

**Gaps in the current framework:**

While the UNCRPD contains some relevant provisions, older people who are not disabled – or do not identify as disabled – may miss out on protection, for example in relation to supported decision making[[16]](#endnote-16) and reasonable accommodations.[[17]](#endnote-17)

Older people experience a number of specific barriers to exercising and asserting their rights.[[18]](#endnote-18) For example, evidence indicates that many older people experience negative attitudes based on their age,[[19]](#endnote-19) [[20]](#endnote-20) a lack of options and control over their living arrangements[[21]](#endnote-21) as well as barriers to choice and control over other parts of their lives,[[22]](#endnote-22) including discrimination in receipt of financial services.[[23]](#endnote-23) [[24]](#endnote-24)

**Proposed normative content:**

It is therefore important to affirm the right of older people to autonomy and independence, and consider including the following normative elements:

* **Equal recognition before the law**, including the right to be recognised as a person before the law and the right to support, as required, to exercise one’s legal and decision-making capacity across all aspects of life.
* **The right to be involved in decisions affecting one’s own life**, including decisions about individual circumstances, and relevant national policy decisions, and the right to have one’s decisions respected.
* **The right to liberty, security and personal integrity** including the right to freedom from arbitrary deprivation of one’s liberty on the basis of age alone, or factors relating to older age.
* **The right to choose where and with whom to live** and not to be forced or pressurised into particular living arrangements, including the right to take risks, within reason, when making choices about living arrangements.
* **The right to access a range of options and appropriate support** to enable choice and control over living arrangements.
* **The right to access a range of in-home, residential and community support services**, including personalised assistance, enabling inclusion in all areas of life.
* **The equal right to access general services within the community**, including housing, transport, shops, banking, financial services, and the internet.
* **The right to reasonable adjustments/accommodations** to ensure access to and inclusion in employment, goods and services.

Corresponding State Party obligations could include undertaking all appropriate legislative, administrative, policy, programmatic and other measures to respect, protect and fulfil the normative elements of the rights to autonomy and independence. Some normative elements will entail immediate obligations, whereas others may be subject to obligations of progressive realisation according to the maximum available resources, following established international human rights principles and jurisprudence.

1. **PALLIATIVE AND LONG-TERM CARE**

**Current framework:**

1. *The right to the highest attainable standard of health:* Palliative care is not explicitly included in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). However, interpretation of Article 12 in relation to older people includes a requirement for States Parties to ensure ‘attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity’.[[25]](#endnote-25)
2. *The right to live independently in the community:* As noted above in relation to autonomy and independence, UNCRPD Article 19 provides specific protection for disabled people’s right to live independently within the community, including Article 19(b) concerning access to individualised support services. UNCRPD Article 26 on habilitation and rehabilitation is also important for enabling people to live independently in their communities.
3. *The right to liberty, security, personal integrity, and freedom from torture, inhuman or degrading treatment:* The normative elements of liberty, security and personal integrity outlined above in relation to autonomy and independence are also relevant to palliative and long-term care. The right to freedom from torture, inhuman or degrading treatment set out in Article 7 of the ICCPR, and in the Convention Against Torture, are also applicable to long-term care settings and in relation to a lack of pain relief in palliative care.[[26]](#endnote-26)

**Gaps in the current framework:**

Palliative[[27]](#endnote-27) and long-term care are central for the dignity and independence of many older people, but evidence indicates that older people experience unequal access to palliative care,[[28]](#endnote-28) with their needs ‘often under assessed and undertreated’.[[29]](#endnote-29) In addition, social care services for older people often fail to provide sufficient support,[[30]](#endnote-30) and older people may be particularly vulnerable to infringement of their liberty, security and personal integrity in care settings,[[31]](#endnote-31) for example through the use of seclusion and restraint.[[32]](#endnote-32)

Palliative care does not receive sufficient or explicit attention within the existing international human rights framework,[[33]](#endnote-33) and there is a need to close this gap to ensure access to holistic palliative care for older people.[[34]](#endnote-34) In relation to long-term care, while the UNCRPD may provide some degree of protection, it falls short of protecting those older people who are not disabled, or do not identify as disabled. [[35]](#endnote-35)

**Proposed normative content:**

Building on the growing body of evidence and analysis referred to above, it is important to affirm the right of older people to palliative and long-term care, and consider including the following normative elements:

* **The right to the highest attainable standard of palliative care,** which should be holistic, encompassing all emotional, social, psychological and physical needs, including but not limited to pain-relief.
* **The right to access adequate pain relief, and to be free from torture, inhuman or degrading treatment** resulting from lack of access to, or inadequate, pain relief.
* **The right to the highest attainable standard of long-term care,** including holistic support to promote independent living, inclusion in the community, and access to habilitation and rehabilitation.
* **The right to participate in long-term and palliative care planning,** including the right to receive information and support for meaningful involvement.
* **The right to personal integrity and to freedom from torture, inhuman or degrading treatment in all care settings,** including the right to be treated with respect and dignity, and freedom from all forms of restraint and seclusion.

Corresponding State Party obligations could include undertaking all appropriate legislative, administrative, policy, programmatic and other measures to respect, protect and fulfil the normative elements of the right to palliative and long-term care. Some normative elements will entail immediate obligations, whereas others may be subject to obligations of progressive realisation according to the maximum available resources, following established international human rights principles and jurisprudence.

**Endnotes:**

1. The Equality and Human Rights Commission (the Commission) is a statutory body established under the Equality Act 2006. It operates independently to encourage equality and diversity, eliminate unlawful discrimination, and protect and promote human rights. The Commission enforces equality legislation on age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. It encourages compliance with the Human Rights Act 1998 and is accredited at UN level as an ‘A status’ National Human Rights Institution, in recognition of its independence, powers and performance. See: <https://www.equalityhumanrights.com/en> [↑](#endnote-ref-1)
2. Vienna Declaration and Programme of Action (1993), available at: <https://www.ohchr.org/en/professionalinterest/pages/vienna.aspx> [accessed: 18 January 2019] [↑](#endnote-ref-2)
3. For example, achieving the right to autonomy and independence for older people depends on the realisation of a range of other rights, including rights to health, work, an adequate standard of living, education and participation. [↑](#endnote-ref-3)
4. OHCHR (2012), ‘Normative standards in international human rights law in relation to older persons – analytical outcome paper’, available at: <https://social.un.org/ageing-working-group/documents/OHCHRAnalyticalOutcomePaperonOldePersonsAugust2012.doc> [accessed: 18 January 2019]. [↑](#endnote-ref-4)
5. UNCRPD General Comment No. 1, para 3, available at: <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en> [accessed: 16 January 2019]. [↑](#endnote-ref-5)
6. Equality and Human Rights Commission (2011), ‘Close to Home: An inquiry into older people and human rights in home care’, available at: <https://www.equalityhumanrights.com/en/inquiries-and-investigations/inquiry-home-care-older-people/download-home-care-report> [accessed: 30 January 2019]. [↑](#endnote-ref-6)
7. See UNCRPD Articles 4(3) and 33(3) in particular, along with UNCRPD General Comment No. 7, available at: <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en> [↑](#endnote-ref-7)
8. UNCRPD General Comment No. 5, paras 24-26, available at: [accessed: 31 January 2019]. <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en> [accessed: 29 January 2019]. Options include accessible housing and support within the community. [↑](#endnote-ref-8)
9. Such as education and political participation, not only in relation to living arrangements: Ibid, para 28-29 [↑](#endnote-ref-9)
10. Including ‘a wide range’ of services such as housing, public libraries, transport, shops and the internet: Ibid, para 32 [↑](#endnote-ref-10)
11. Ibid, paras 33-37. [↑](#endnote-ref-11)
12. Alongside UNCRPD General Comment No. 2, available at: <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en> [accessed: 29 January 2019]. [↑](#endnote-ref-12)
13. Note that ‘accessibility’ and ‘reasonable accommodation’ duties are distinct within the UNCRPD. In particular, accessibility duties are *ex* ante/anticipatory, reasonable accommodations are *ex nunc*/after the event. See UNCRPD General Comment No. 6, paras 23-24, available at: <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en> [accessed: 31 January 2019]. [↑](#endnote-ref-13)
14. In addition, guidelines on UNCRPD Article 14 make it clear that anyone deprived of their dignity must be treated with respect for their personal integrity. See: <https://www.ohchr.org/Documents/HRBodies/CRPD/GC/GuidelinesArticle14.doc> [↑](#endnote-ref-14)
15. Equality and Human Rights Commission (2011), ‘Close to Home: An inquiry into older people and human rights in home care’, available at: <https://www.equalityhumanrights.com/en/inquiries-and-investigations/inquiry-home-care-older-people/download-home-care-report> [accessed: 30 January 2019]. [↑](#endnote-ref-15)
16. OHCHR (2012), ‘Normative standards in international human rights law in relation to older persons – analytical outcome paper’, page 22, available at: <https://social.un.org/ageing-working-group/documents/OHCHRAnalyticalOutcomePaperonOldePersonsAugust2012.doc> [↑](#endnote-ref-16)
17. <https://www.age-platform.eu/policy-work/news/extending-reasonable-accommodation-older-people> [accessed: 18 January 2019]. [↑](#endnote-ref-17)
18. For an overview of some key issues in Great Britain, see: Age UK (2018) ‘Ageism and Age Equality (Great Britain) – Policy Position Paper’, available at: <https://www.ageuk.org.uk/globalassets/age-uk/documents/policy-positions/cross-cutting-issues/ageism-and-age-equality-pp-great-britain-august-2018.pdf> [accessed: 18 January 2019]. [↑](#endnote-ref-18)
19. RSPH (2018), ‘That Age Old Question: How attitudes to ageing affect our health and wellbeing,’ available at: <https://www.rsph.org.uk/uploads/assets/uploaded/010d3159-0d36-4707-aee54e29047c8e3a.pdf> [accessed: 28 January 2019]. [↑](#endnote-ref-19)
20. Women and Equalities Committee (2018), ‘Older people and employment’, available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmwomeq/359/359.pdf> [accessed: 28 January 2019]. [↑](#endnote-ref-20)
21. EHRC (2018), ‘Is Britain Fairer? The state of equality and human rights 2018, p. 83, available at: <https://www.equalityhumanrights.com/en/publication-download/britain-fairer-2018> [accessed: 28 January 2019]. See also: EHRC (2018), ‘Housing and disabled people: Britain’s hidden crisis’, available at: <https://www.equalityhumanrights.com/en/publication-download/housing-and-disabled-people-britains-hidden-crisis> [accessed: 28 January 2019]. [↑](#endnote-ref-21)
22. All Party Parliamentary Group on Ageing and Older People (2018), ‘Inquiry into human rights and older people: Protecting rights as we age’, available at: <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/appg/appg_ageingandolderpeople_humanrights_jun18.pdf> [accessed: 18 January 2019]. [↑](#endnote-ref-22)
23. Such as mortgages and travel insurance. The Equality Act 2010 does not currently require service providers not to discriminate against people because of their age or the age group to which they belong. See: [htttps://www.equalityhumanrights.com/en/advice-and-guidance/equality-law-banks-and-other-financial-services-providers](https://www.equalityhumanrights.com/en/advice-and-guidance/equality-law-banks-and-other-financial-services-providers) [accessed: 18 January 2019]. [↑](#endnote-ref-23)
24. Financial Conduct Authority (2016), ‘Access to Financial Services in the UK’, pp 106 – 118, available at: <https://www.fca.org.uk/publication/occasional-papers/occasional-paper-17.pdf> [accessed: 14 January 2019], and Financial Services Ombudsman (2015), ‘Just a number? age, complaints and the ombudsman’, available at: <https://www.financial-ombudsman.org.uk/publications/policy-statements/age-insight-briefing-2015.pdf> [accessed: 14 January 2019]. [↑](#endnote-ref-24)
25. ICESCR General Comment No. 14, para 25, available at: <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2f2000%2f4&Lang=en> [accessed: 14 January 2019]. This General Comment also states that states must not deny access to health services, including palliative care, for any group including older persons (para 34). [↑](#endnote-ref-25)
26. Human Rights Council (2009), ‘Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowa’, A/HRC/10/ 44. 2009. para 72, available at: <https://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf> [accessed: 14 January 2019]. [↑](#endnote-ref-26)
27. Palliative care has been defined by the World Health Organisation as: ‘The active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and pf psychological, social and spiritual problem is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families.’ See: <https://www.who.int/cancer/palliative/definition/en/> [accessed: 28 January 2019]. [↑](#endnote-ref-27)
28. Dixon, J. et al (2015), ‘Equity in the provision of palliative care in the UK: Review of evidence’, available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf> [accessed: 28 January 2019]. [↑](#endnote-ref-28)
29. Pal, M. and Manning, L., ‘Palliative care for frail older people’, Clinical Medicine, available at: <http://www.clinmed.rcpjournal.org/content/14/3/292.full> [accessed: 28 January 2019]. . See also: <https://www.bgs.org.uk/blog/palliative-care-for-frail-older-people-what-when-and-how> [accessed: 28 January 2019]. [↑](#endnote-ref-29)
30. Humphries, R. et al (2016), ‘Social care for older people: Home truths’, available at: <https://www.kingsfund.org.uk/publications/social-care-older-people> [accessed: 14 January 2019]. and Age UK (2018), Why call it care when nobody cares?’, available at: <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/RB_mar18_social_care_campaignreport.pdf> [accessed: 28 January 2019]. [↑](#endnote-ref-30)
31. EHRC (2011), ‘Close to home: An inquiry into older people and human rights in home care’, available at: <https://www.equalityhumanrights.com/en/publication-download/close-home-inquiry-older-people-and-human-rights-home-care> [accessed: 28 January 2019], and Care Quality Commission (2017), ‘The State of adult social care services 2014 – 2017’, available at: <https://www.cqc.org.uk/publications/major-report/state-adult-social-care-services-2014-2017> [accessed: 28 January 2019]. [↑](#endnote-ref-31)
32. For evidence on the prevalence of chemical restraint via antipsychotic drug prescriptions, see: Szczepura, A. et al (2016), ‘Antipsychotic prescribing in care homes before and after launch of a national dementia strategy: an observational study in English institutions over a 4-year period’, BMJ Open, available at: <https://bmjopen.bmj.com/content/6/9/e009882> [accessed: 14 January 2019]. [↑](#endnote-ref-32)
33. Ezer. T., et al. (2018), ‘Palliative Care and Human Rights: A Decade of Evolution in Standards’, Journal of pain and Symptom Management, Vol 55, No 2S, available at: <https://www.jpsmjournal.com/article/S0885-3924(17)30371-8/pdf> [accessed: 25 January 2019]. See also: <https://www.opensocietyfoundations.org/sites/default/files/palliative-care-human-right-fact-sheet-20160218.pdf> [accessed: 25 January 2019]. [↑](#endnote-ref-33)
34. Human Rights Council (2015), ‘Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte’, A/ HRC/30/43, paras 87 and 131, available at: <https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_43_ENG.docx> [accessed: 25 January 2019]. [↑](#endnote-ref-34)
35. ENNHRI (2017), ‘”We have the same rights”: The human rights of older persons in long-term care in Europe’, p. 77, available at: <http://www.ennhri.org/IMG/pdf/ennhri_hr_op_web.pdf> [accessed: 25 January 2019]. [↑](#endnote-ref-35)