

# Consultation Response

## UN Call for Submissions for the ninth session of the Open-Ended Working Group on Ageing

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## About this consultation

The UN has issued a call for written submissions to support the preparation for the ninth session of the Open-Ended Working Group on Ageing (OEWG) in July 2018. The call is for substantive inputs on the two new focus areas of **Long term and palliative care**, and **Independence and autonomy**. There has also been a call for inputs in the form of normative content for a possible international instrument on the two focus areas that were discussed in the eighth session of the OEWG in July 2017, **Equality and non-discrimination**, and **Violence, neglect and abuse**.

## Key points and recommendations

- Despite existing domestic human rights and equalities legislation, older people in the UK continue to face extensive discrimination and human rights abuses in their daily lives that curtail their ability to live independently and autonomously.
- Funding for older people's social care in the UK has suffered devastating cuts in recent years leaving the provision of this care in a state of crisis. This under-funding poses a real threat to older people's ability to uphold their independence and autonomy as they lose control over daily activities and where and when they receive social care.
- Ageism and discrimination prevents many older people from accessing health, financial services, housing and employment, which increases their dependence on others, thereby depriving them of the ability to live independently and autonomously.
- Age UK strongly believes that a UN Convention on the rights of older persons which has at its core an emphasis on promoting and protecting older people's rights to autonomy and independence and support for independent living would address these issues.
- A right to palliative care situated within a UN Convention on the rights of older persons could encompass a right to choose where to die, to refuse medical treatment or to withdraw consent, a right to equal access to holistic palliative care without delay, including pain relief, and access to end of life care, including making advance instructions on the type of care provided.

## **1. Introduction**

Age UK is a national charity that works with a network of partners, including Age Scotland, Age Cymru, Age NI and local Age UKs across England, to help everyone make the most of later life, whatever their circumstances. In the UK, the charity helps more than seven million older people each year by providing advice and support. It also researches and campaigns on the issues that matter most to older people. Its work focuses on ensuring that older people have enough money; enjoy life and feel well; receive high quality health and care; are comfortable, safe and secure at home; and feel valued and able to participate.

Internationally, we support programme and policy work in lower- and middle-income countries through our partner and subsidiary charity Age International, who has contributed to this submission. Age International is an active member of the HelpAge Global Network and the Global Alliance for the Rights of Older People, a large and growing coalition of civil society organisations world-wide working to strengthen older people's rights globally.

Age UK and Age International firmly believe that a UN Convention on the rights of older persons would provide a framework and focus to guide policy responses to ageing based on rights, equity and social justice. It also has the potential to create a shift from older people being considered as passive recipients of welfare, to older people as active rights holders and to reduce the level of abuse, neglect and discrimination experienced by many older people.

## **2. Autonomy and independence**

### **2.1 How is the right to autonomy and independence of older persons defined in legal and policy frameworks in the UK?**

The Human Rights Act 1998 incorporates the Articles of the European Convention on Human Rights into UK law. Article 8 gives rise to the right to a private and family life, giving older people the right to make their own choices about whether they would like to accept or refuse medical treatment, as well as enabling them to make their own choices as far as possible when in residential care or hospital.

The Care Act 2014 provides a right to an assessment of needs and support to meet any identified needs in line with a set of 'wellbeing principles' which include protecting the rights of people to self-determination and maintaining a sense of identity, supporting them to live as active members of society with dignity and without fear of abuse and neglect.

UK age discrimination laws stem from EU treaty provisions and directives, but these have been incorporated into domestic legislation, notably through the Equality Act 2010 which provides a set of legislative tools for tackling age discrimination both within the realm of employment and in the provision of goods and services.

The Mental Capacity Act 2005 provides a legal framework to empower and protect people who cannot make specific decisions for themselves. It supports those with mental capacity to plan for the future, by giving legal status to an advance decision to refuse treatment and a Lasting Power of Attorney.

## **2.2 The key issues and challenges facing older persons in the United Kingdom regarding autonomy and independence**

Despite the aforementioned legal instruments, older people continue to face extensive discrimination and human rights abuses in their daily lives that not only rob them of their dignity but also their ability to live independently and autonomously. These legal frameworks are not unfit for purpose, rather they do not fully address the particular issues relating to older people and ageism and they are undermined by poor implementation.

### Social care funding

Funding for older people's social care in the UK has suffered devastating cuts in recent years leaving the provision of this care in a state of crisis. This under-funding poses a real threat to older people's ability to uphold their independence and autonomy as they lose control over daily activities and where and when they receive social care.

Significant cuts to social care funding mean that fewer older people in the UK, proportionately, are eligible for social care support. The result is that there are now more than a million older people who have difficulty with daily living activities such as eating, bathing and taking their medication, whose needs are not fully met by either paid or unpaid carers thereby severely limiting their ability to live independently.<sup>1</sup>

A right to independent living is enshrined in Article 19 of the UNCRPD. However, despite the UK having ratified the UNCRPD, independent living does not currently exist as a freestanding, justiciable right in UK law. Moreover the UNCRPD does not cover the broader circumstances of older people who are not considered to be living with a disability. There is also a clear implementation gap with many older people not receiving services adequate to uphold independence and autonomy. The development of personalised care for older people has lagged behind care and support for other groups, with older people less likely to have choice and control over what support they receive and less likely to receive care and support in their own home, where most would prefer to live.<sup>2</sup>

For too many older people who lack mental capacity, restrictive care or treatment is being sanctioned as a first measure rather than as a measure of last resort with many older people being unlawfully deprived of their liberty in care and health settings through a misuse of measures available under the Mental Capacity Act.

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<sup>1</sup> See the Care Quality Commission, [The state of health care and adult social care in England 2016/17](#), October 2017.

<sup>2</sup> Age UK, [Independence and Personalisation \(England\)](#), 2016.

Under the Act, care homes and hospitals have to seek authorisation for a 'Deprivation of Liberty Safeguard' (DOLS) if they consider they are already in, or may have to move a person into, more restrictive care of treatment in that person's 'best interests'. Ultimately, this deprives a person of liberty, which is why it is necessary to seek a DOLS under the Mental Capacity Act.

Funding cuts to social care have meant that people are unable to receive the social care at home that they and their families need and prefer, and therefore people have to be moved to a care home, often against their will. Despite the legislation, underfunded councils are not properly resourced to undertake the assessments of deprivation of liberty, as well as reviewing cases in the necessary timescales. As a result, there are many people whose deprivation does not have suitable conditions placed on it or should not be occurring at all.<sup>3</sup>

### Discrimination

Ageism and discrimination prevent many older people from accessing health, financial services, housing and employment. A deterioration in health or income or access to services that encourage financial independence increases peoples' dependence on others, thereby depriving them of the ability to live independently and autonomously.

In health and social care, there is compelling evidence of the harmful effects of age discrimination. Research demonstrates that older people have poorer access to treatments for common health conditions. Treatment rates drop disproportionately for people over 70-75 years in areas such as surgery<sup>4</sup>; chemotherapy<sup>5</sup>; and talking therapies<sup>6</sup>.

A broad exception for financial services in the Equality Act 2010 restricts older people's access to essential products including loans, mortgages, travel and motor insurance, making it harder for older people to shop around for the best products.<sup>7</sup>

In employment, unjustified age discrimination is still rife, in spite of it being illegal under the Equality Act 2010. Polling by YouGov commissioned by Age UK in 2017 found that 36% of over 50s felt they had been disadvantaged at work because of their age.

### Independence and accessibility

Lack of public transport, or somewhere to sit down, or access to clean public toilets limits how far older people are able to get around and poor quality pavements, poor street lighting or fear of crime can stop people feeling confident enough to go out at all. This

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<sup>3</sup> See the Select Committee on the Mental Capacity Act 2005, [Mental Capacity Act 2005: post-legislative scrutiny](#), House of Lords, 2014.

<sup>4</sup> Age UK/Royal College of Surgeons, [Access all ages - Assessing the impact of age on access to surgical treatment](#), 2012

<sup>5</sup> NHS England, [Are older people receiving cancer drugs? An analysis of patterns in cancer drug delivery according to the age of patient](#), 2013.

<sup>6</sup> Age UK, [Hidden in plain sight - the unmet mental health needs of older people](#), 2016

<sup>7</sup> Financial Conduct Authority, [Access to Financial Services in the UK](#), 2016

limits people's ability to participate in family, social, cultural, community and political life. The characteristics of rural areas, with low population densities and large distances between residential and/or commercial centres, can exacerbate the challenges older people face.<sup>8</sup>

Many older people have physical disabilities yet only 3.6 per cent of homes have the four essential features that would make them accessible to a person with mobility problems (level access to main entrance, flush threshold to main entrance, WC at entry level and circulation space).<sup>9</sup> This severely limits people's ability to have control over their living arrangements.

### Rights to autonomy and independence

Age UK strongly believes that a UN Convention on the rights of older persons which has at its core a strong emphasis on promoting and protecting older people's rights to autonomy and independence and support for independent living would address these issues. A fuller articulation of the rights to autonomy and independence, housing, essential services and employment within a convention which recognises that personal autonomy and independence are essential components would allow older people to claim it more effectively. Equally important, it must also be recognised that the undignified care and treatment of older people does not happen in a vacuum; these are rooted in the discrimination evident towards older people across society. Age discrimination must also be explicitly prohibited by a convention.

## **3. Palliative and long-term care**

### **3.1 How is palliative and long-term care for older persons defined and provided for in legal and policy frameworks in the United Kingdom?**

Under the Health and Social Care Act 2012, the Secretary of State for Health has a duty to promote a comprehensive health service, which is universal and free at the point of need. This can include long-term care where this relates to a 'primary health need'. More standard support relating to social care needs, i.e. practical assistance or accommodation to help someone undertake activities of daily living is covered by the Care Act 2014 but this is heavily means and needs tested.

People can be referred to specialist palliative care as part of their right to healthcare, so it is defined in 'legal frameworks' insofar as being delivered by registered professionals; recommended by the body responsible for setting clinical guidelines; and assessed within broader performance management mechanisms of the health service.

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<sup>8</sup> Holley-Moore, G. & Creighton, H., *The Future of Transport in an Ageing Society*, Age UK and ILC, 2015.

<sup>9</sup> Oto, S., *Housing an Ageing Population (England)*, The House of Commons, 2015.

### **3.2 What are the specific challenges faced by older persons in accessing long-term care?**

Significant cuts to social care funding mean that fewer older people, proportionately, are eligible for social care support. Those that are getting it are often receiving a cut-down service that does not give full regard to the wellbeing principles laid out in legislation or even basics of dignity and respect. Support visits can be very short and perfunctory and the quality of care homes (which as a sector is under great financial pressure) can be highly questionable.<sup>10</sup> Principles of prevention and improving wellbeing are often considered secondary, or even tertiary, to fulfilling basic tasks. An over-arching issue is that the financial means-test used when establishing how assessed needs will be met is opaque and confusing and comes down hard on people that have a single large asset like a house.

A UN convention has the potential to focus greater attention on the provision of long-term care, which has long been seen as less important than healthcare. There should be a right to services that promote and maintain people's ability to live independently and autonomously.

### **3.3 What are the specific needs and challenges facing older persons regarding end-of-life care?**

As a medical speciality the UK is generally seen as a pioneer of palliative care, though this is not always played out in the experiences of many individuals and their families. Despite palliative care being defined in the legal frameworks in the form of continuing healthcare, it isn't always being adequately provided. Research shows that many older people experience unnecessary pain and other symptoms, being treated with a lack of dignity and respect, and many people do not die where they would choose to.<sup>11</sup> People over 80 experience the worst overall quality of care in the last two days of life compared with other age groups, covering such areas as pain relief, nutrition and emotional needs. Care pathways for many older people with multiple or non-specific health problems are not agile enough to respond to needs that can change very rapidly and unexpectedly or where preparation for potential changes hasn't taken place.<sup>12</sup>

Historically, you are more likely to have access to palliative care when you are in the end stages of a terminal disease and less likely if you are at the end of life with no one specific disease, i.e. older people are less likely to receive it. This also goes for hospice care, which you are less likely to get as an older person for the same reasons. The National Health Service will fund some hospice beds in the community, but they remain largely funded as charitable organisations.<sup>13</sup>

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<sup>10</sup> Care Quality Commission, [The state of health care and adult social care in England 2016/17](#), October 2017.

<sup>11</sup> Age UK, [End of life evidence review](#), 2013 and Offices for National Statistics, [National Survey of Bereaved People \(VOICES\)](#), 2014

<sup>12</sup> Royal College of Physicians, [End of Life Care Audit- Dying in Hospital: National report for England](#), 2016.

<sup>13</sup> Dixon, J., King, D., Clark, M., & Knapp, M., [Equity in the Provision of Palliative Care in the UK: Review of Evidence](#), London School of Economics, 2015.

One of the key issues is a poor understanding of the trajectory of multimorbidity and frailty. How someone deteriorates when they live with multiple health conditions and general frailty, which will be how most people die, is less well understood than terminal diseases and thus advance planning and access to services are less forthcoming. This can result in an older person not getting access to adequate support and having the final days of their life complicated by multiple readmissions and discharges from hospital.

### **3.4 A right to a palliative care**

A right to palliative care situated within a UN Convention on the rights of older people could encompass a right to choose where to die, to refuse medical treatment or to withdraw consent, a right to equal access to holistic specialist palliative care without delay, including pain relief, and equal access to responsive, compassionate care that effectively manages people at the end of life, including making advance instructions on the type of care provided. This could have significant beneficial impacts in the UK context where concerns remain about the protection of human rights at the end of life. It would not necessarily require new standard setting but would bring renewed focus to efforts to protect human rights of older people at the end of life.



## 4. Normative content for the right to equality and non-discrimination

Older people have the right to equality and freedom from discrimination on the basis of their age or any other ground, alone or in combination with another ground or grounds.

### Equality

- Equality in older age is the full participation and inclusion of older people in all aspects of society based on the equal respect for the dignity of older people.
- The right should contain a range of general obligations on States to ensure both formal and substantive equality in older age, including a duty to consider the differential impact of all their decisions, including but not limited to age-based policies, on older people.
- Special measures, namely proactive measures that ensure older people benefit from equality and non-discrimination in practice and that offer a genuine benefit to address disadvantage, should be allowed.

### All forms of discrimination

- The prohibition of and guarantee of legal protection against discrimination in older age should apply to every aspect of life.
- All forms of discrimination should be prohibited, including direct, indirect, by association, by perception or imputation, and harassment.
- The prohibition of discrimination in older age should not be subject to a wider range of exceptions to the principle of equal treatment than is permitted for any other prohibited ground. Any exceptions, including age proxies, require specific justification.

### Multiple discrimination

- Intersectional discrimination, namely the combined effect of age and another personal characteristic or the combined effect of any two or more characteristics, should be prohibited.
- Cumulative discrimination, namely discrimination on a number of occasions over time, should be prohibited.
- The intersectional and cumulative discrimination experienced by older women should be highlighted.

### Ageism and structural discrimination

- Both discrimination against an individual and harmful ageist social norms and practices should be prohibited.
- States should have an obligation to take steps to eliminate harmful ageist social norms and practices, including but not limited to raising awareness of the rights and capacities of older people; countering any discriminatory ageist perceptions and practices towards older age and older people; and, eliminating any harmful traditional practices and institutional, systemic or structural practices which adversely affect the human dignity or personal security of older people.

### Remedies, sanctions and enforcement

- States should assist older people in making claims and accessing justice by providing information on remedies and how to access them; legal assistance and legal aid; a hearing within reasonable time with special measures in situations of immediacy; and, accommodations in judicial proceedings to facilitate older people's effective role as participants.
- States should take account of accumulating discrimination when fashioning redress and reparation for age discrimination, including where appropriate in any award of damages.

## **5. Normative content for the right to freedom from violence, abuse and neglect**

Older people have the right to freedom from violence, abuse and neglect.

### All forms of violence, abuse and neglect

- The right to freedom from violence, abuse and neglect in older age should include all forms of violence, abuse and neglect against older people.

### Public and private spheres

- The right should apply to violence, abuse and neglect in private and public settings.
- Acts perpetrated by both private and public actors should fall under the right.
- States may be responsible for private acts of violence, abuse and neglect against older people if they fail to act with due diligence to prevent, protect, prosecute, punish and provide redress for the harm suffered.

### Prevention

- States should have an obligation to take steps to prevent violence, abuse and neglect in older age in relation to, inter alia, legislation and its effective implementation; training of care providers, health care and social workers, the judiciary and law enforcement; appropriate needs assessments, regulation and monitoring of situations of care and support provision; public prevention campaigns; and research into the intersectional drivers of violence.

### Support services

- The right should provide for access to a range of support services for survivors of violence, abuse and neglect, including but not limited to a full range of medical, psychosocial, rehabilitative and legal services; access to information about available support and services; access to appropriate victims support services; and access to effective remedies and redress.

### Remedies and redress

- The right should provide an obligation on states to assist survivors with making complaints.
- The right should provide an obligation on states to investigate and lay criminal charges.

- The state should begin with the assumption that the individual is best placed to judge his or her own well-being and observe self-determination for the survivor.
- Criminal justice responses, criminal offences and sentencing practices should reflect the aggravated nature of offenses against older people.
- Older age should not limit compensatory damages or access to survivor services.

#### Data and statistics

- The right should provide an obligation on states to collect, disaggregate, analyse, utilise and make public at regular intervals appropriate information and statistical data on all forms of violence, abuse and neglect for people of all ages.
- This should include prevalence and trends, risk factors, perpetrators, access to support services and effective remedies and redress.
- Age UK and Age International firmly believe that a UN Convention on the rights of older persons would provide a framework and focus to guide policy responses to ageing based on rights, equity and social justice and has the potential to create a shift from older people being considered as passive recipients of welfare, to older people as active rights holders and reduce the level of abuse, neglect and discrimination experienced by many older people.
- All information gathering and research should comply with internationally accepted norms and ethical principles in the collection and use of statistics and legally established safeguards and should respect the privacy and confidentiality of older people.