

ENNHRI Submission to the OEWG-Ageing: Long-term and Palliative Care

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Introduction

The European Network of National Human Rights Institutions (ENNHRI) brings together over 40 NHRIs¹ across the wider European region. ENNHRI's goal is to enhance the protection and promotion of human rights throughout Europe by assisting in the establishment and accreditation of NHRIs; co-ordinating exchange of information and best practice between members; facilitating capacity building; engaging with regional mechanisms; and intervening on legal and policy developments in Europe. ENNHRI is one of four regional networks of NHRIs, which together make up the Global Alliance of NHRIs (GANHRI).

The Human Rights of Older Persons & Long-term Care

Between 2015-2017, ENNHRI carried out a European Commission-funded project, *The Human Rights of Older Persons and Long-term Care* to improve the human rights of older persons in LTC, with particular emphasis on residential care. The outcomes of the Project were widely disseminated at the OEWG's 8th Session last year, including at a joint EU-ENNHRI Side Event (on Friday 7th July).² These findings included an overview of the human rights concerns identified through pilot monitoring work carried out as part of the Project in Belgium, Croatia, Germany, Hungary, Lithuania and Romania, particularly in upholding dignity, the right to privacy, autonomy, participation, and access to justice. In particular, the findings highlighted the challenges individuals can face in having their choice of where to receive LTC heard, in having their legal capacity respected and in accessing services. Textual analysis carried out by ENNHRI also highlighted that international human rights standards do not provide older people with an explicit right to long-term care and grey area in terms of the obligations of private (for- and non-profit) LTC providers.³

¹ National Human Rights Institutions (NHRIs) are state-mandated bodies, independent of government, with a broad constitutional or legal mandate to protect and promote human rights at the national level. A list of the A-status members is available on request.

² More information on the Project can be found at its dedicated website: <http://ennhri.org/rights4elders>

³ ENNHRI, 2017, *The Application of International Human Rights Standards to Older Persons in Long-term Care*. http://ennhri.org/IMG/pdf/ennhri_application_of_human_rights_to_ltc_feb_2017.pdf.

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Members' Current Work on Ageing

In February-March 2018, ENNHRI members were invited to participate in a survey on the work they do to protect and promote the human rights of older persons. A total of 20 of ENNHRI's 42 members (45%) completed the survey. The findings showed that members were highly engaged in activities related to the rights of older persons, most notably related to monitoring rights protection, advising government and various activities to raise the awareness of various local, national and international stakeholders of the rights of older persons, and are key stakeholders for the OEWG.

All but one of the survey's 19 respondents carry out activities to protect and promote the rights of older persons in or seeking access to long-term care. This included awareness raising activities (14 members) such as roundtable events with relevant stakeholders on the rights of older persons, training sessions, press releases and other media work. Four NHRIs had made toolkits or other training materials for care homes. Fourteen members carried out monitoring and inspection visits/special investigations into care homes, some of which were based on complaints received by the Institution. Several others carried out activities intending to improve the human rights situation of older persons in receipt of long-term care, such as through the provision of training on a human rights-based approach to care, providing recommendations to government (including on proposed and current legislation), meeting relevant stakeholders and writing manuals and other publications. One NHRI had carried out a nationwide initiative aiming to ensure care home providers facilitated older persons' right to vote. Several had installed complaints boxes in care homes and provided information to residents about opportunities to complain or discuss their concerns, including the provision of the institution's own hotline number.

Several members reported human rights concerns in long-term care which mirrored findings from ENNHRI's project, including potentially degrading treatment of older persons in one jurisdiction, as well as inadequate provision of and access to services and access to justice.

Only three respondents to the survey had engaged in activities on palliative care, including making recommendations to government about expanding palliative care services, making recommendations about expanding the scheme of reimbursable medicines to include those on pain relief, monitoring palliative care services and issuing opinions on legislation regarding access to palliative care. This lack of focus on palliative care, which perhaps highlights that NHRIs are lagging behind concerted efforts by governments, civil society organisations and academic institutions to expand service provision and broaden understanding of the service from a narrow interpretation of terminal care to embrace symptom control and psychosocial support for individuals to live as well as possible (for as long as possible) while living with a life-threatening illness, provided by a multidisciplinary team. Palliative care is fundamental to health and dignity and is increasingly recognised as a key element of the right to the highest attainable standard of health (Art. 12 of the UN International Covenant on Economic, Social and Cultural Rights).

Implications for the Human Rights Legislative Framework

International and regional human rights standards do not explicitly provide for the right to either long-term or palliative care. The findings from ENNHRI's project and membership survey indicate that protection may be inadequate in the context of rising health and long-term care costs vis-à-vis other groups.

Recommendation

ENNHRI underlines that all actors must work towards the effective implementation of existing human rights standards to protect the human rights of older persons. At the same time, given the normative and implementation gaps in existing international and regional human rights legislation outlined in this statement, ENNHRI recommends a new Convention on the Rights of Older Persons,⁴ which includes for the right to long-term and palliative care.

⁴ ENNHRI is aware of the challenges faced in drafting a Convention for the Rights of Older Persons, not least in defining the term 'older person'. From NHRIs' experience of working on older persons' human rights, ENNHRI stands ready to input to this process.