

The key elements of the normative content for the development of a possible international standard on the protection of the rights of older people to Long Term Care and Palliative Care and the right to Autonomy and Independence.

A. Introduction

This joint submission of the German Institute for Human Rights and the Commissioner for Human Rights of the Republic of Poland (both A Status NHRIs) is based on conclusions from discussions at an expert workshop held at the German Institute for Human Rights on 22 January 2019. The contribution made by some 15 experts is gratefully acknowledged.

This input is intended to advance the discussion on the content of an international instrument. Both institutions are of the firm view that a binding international instrument would provide the strongest protection for the rights of older persons.

Following discussions at the 8th and 9th sessions of the OEWG, the decision to invite relevant stakeholders to submit normative content on the thematic areas discussed is welcome. We wish to highlight the importance of referring to such principles as the dignity, autonomy and independence of older persons and non-discrimination in the preamble of the new international instrument, which should be elaborated as a binding convention on human rights of older persons. These principles should be affirmed in the preamble and in the text of the new convention, which should also identify the barriers to the full enjoyment of human rights and fundamental freedoms by older persons.

Moreover, any new instrument should satisfy the following conditions:

- a) The new instrument should not lower existing international human rights standards.
- b) A new convention needs to declare clearly that States are the duty bearers.
- c) The instrument should state that the rights holders are older persons, who constitute a heterogeneous group of persons of various capabilities and needs.
- d) The new instrument should stress the positive potential of older persons and guarantee the enjoyment of their capabilities and human rights on an equal basis.
- e) The instrument should indicate the changing technologies which will play a role in the lives of older persons and ageing societies in the future and frame them in the context of human rights.

The rights to high quality long term-care and palliative care should be formulated as separate rights¹. Autonomy and independence for older persons should be framed both as a principle and a right.

B. Normative elements of the right to long term care:

Older persons have the right to accessible and affordable long-term care services of good quality, in particular home-care and community-based services² without discrimination of any kind.

The right to long term care should include guarantees of:

- accessible information and support to decision making
- dignity, physical and mental integrity, freedom and security
- self-determination, autonomy and independence
- freedom of expression and freedom of thought/conscience: convictions, beliefs and values
- privacy
- continued communication, participation in society and cultural activity
- high quality, comprehensive³, holistic, person-centred and tailored care
- advice, free and informed consent⁴ in medical and other matters
- choice of services
- access to long term care in a setting that is consistent with their needs, will and preferences, including in public and private settings
- equal access to long term care without discrimination
- access to palliative care
- respect in dying and in death
- the monitoring of the quality of long-term care and service
- a complaint mechanism and redress for violation of the right.⁵

States shall take appropriate and effective measures:

- to promote, maintain and improve the health and well-being of older persons.
- to prevent the loss of capabilities and health of older persons which would lead to or would increase their need of long-term care.

¹ European Pillar of Social Rights (Chapter 3, art. 18), proclaimed by the European Parliament, the Council and the European Commission at the Social Summit for Fair Jobs and Growth in Gothenburg on 17 November 2017.

² European Pillar of Social Rights (Chapter 3, art. 18), proclaimed by the European Parliament, the Council and the European Commission at the Social Summit for Fair Jobs and Growth in Gothenburg on 17 November 2017.

³ COE PACE Res. 2168 (2017) Human rights of older persons and their comprehensive care.

⁴ See also Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Art. 5 and art 10.

⁵ According to the European Charter of the Rights and Responsibilities of Older People in Need of Long-term Care and Assistance.

- to operate a well-coordinated system⁶ encompassing medical, social care⁷ and support by volunteers in all kind of settings.
- to ensure that older persons may, on the basis of informed consent, themselves choose appropriate care support services’.
- to introduce effective services providing information about available support services.
- to ensure proper working conditions and adequate training for formal and informal carers including volunteers⁸.
- to ensure that care delivery is regulated and assessed.
- to ensure adequate, effective mechanisms for older persons to complain and seek redress.
- to prevent isolation and social exclusion of older persons in long term care.
- to provide support to informal carers and encourage them to stay longer in the labour market.

C. Normative elements of the right to palliative care:

Older persons have the right to accessible and affordable long-term care services of good quality, in particular home-care and community-based services without any discrimination.

The States shall anticipate the need of pain relief at some stage of life and introduce palliative care also as a preventive measure. Functioning of these mechanisms shall be assessed and evaluated.

The right to palliative care should include guarantees of :

- accessible information and support to decision making
- dignity, physical and mental integrity, freedom and security
- self-determination, autonomy and independence
- freedom of expression and freedom of thought/conscience: convictions, beliefs and values
- privacy
- continued communication, participation in society and cultural activity
- high quality, comprehensive, holistic, person-centred and tailored care
- advice, free and informed consent in medical and other matters
- choice of services

⁶ *Proposal for Regulation of the European Parliament and of the Council amending Regulation (EC) No 883/2004 on the coordination of social security systems*, presented by the European Commission in 2016. See also the Madrid International Plan of Action on Ageing 2002.

⁷ Inter-American Convention on Protecting the Human Rights Of Older Persons (A-70) (I-ACOPR 2015) - Article 12 Rights of older persons receiving long-term care; Council of Europe: Committee of Ministers, *Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons*, 19 February 2014, (CM/Rec(2014)2), IV care, General Principles.

⁸ In its report *Care work and care jobs for future decent work* (2018) the International Labour Organisation indicates that the statistics standards include unpaid care as work since 2013.

- access to palliative care in a setting that is consistent with their needs, will and preferences, including in public and private settings
- equal access to palliative care without discrimination
- respect in dying and in death
- the monitoring of the quality of palliative care and service
- a complaint mechanism and redress for violation of the right.

States shall take appropriate and effective measures:

- to ensure quality palliative care is available, acceptable and accessible for older persons.
- to integrate palliative care into the public health system and universal health coverage.
- to ensure the adequate training in palliative care of health, social and spiritual care providers and volunteers.
- to enable timely access to information about available options for palliative care support and services.
- to enable access to essential technologies and medicines, including internationally controlled essential medicines, for palliative care of older persons including the treatment of moderate to severe pain.
- to review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes.
- to recognize in national legislation the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering.
- to remove regulatory, educational, and attitudinal obstacles that restrict the availability to essential palliative care medications.
- to put in place measures to safeguard against the misuse of narcotic and psychotropic drugs and other medications.
- to prevent the cruel, inhuman and degrading treatment of older persons, including as a result of the failure to provide adequate care and adequately treat pain, discomfort and other symptoms.
- to ensure older persons are able to express their free, prior and on-going informed consent to their palliative care and overall health and social care.
- to facilitate the preparation of advance directives, living wills or legally binding documents by which older persons may indicate their preferences in relation to all their palliative care options from diagnosis to end of life care.
- to provide timely information about any changes in legislation that may affect the operation of advance directives and enable a periodic revision of the personal directives.
- to ensure older persons have access to palliative care in a setting that is consistent with their needs, will and preferences, including at home or in long-term care settings.
- to ensure that older persons are able to exercise their legal capacity in this area, while providing for supported decision-making where necessary.
- to ensure that, where necessary, older persons have access to a range of supports to exercise their legal capacity, including the appointment of one or more trusted persons to

- assist them to make decisions based on their instructions, will and preferences.
- to ensure those close to the older person, including family members, are able to access support in form of a range of services including support in going through administrative procedures related to care related to care, end of life and bereavement.
 - To put in place measures to safeguard against the misuse of narcotic and psychotropic drugs and other medications.
 - to regulate and monitor the compliance of all palliative care providers with professional obligations and standards.

The accountability of States in regard to ensuring the right to long-term care and palliative care shall include provision relating to such matters as:

- financial – ensuring compliance with explicit financial reporting procedures,
- performance – achieving defined or prescribed, measurable outputs, which involves such activities as assessing the need for long-term and palliative care, adopting strategies and action plans encompassing financing the development of needed services in the long-term in light of the increasing number of older persons, and assessing the results by comparing the outcomes achieved against the plans.
- political - fulfilling public trust by creating an appropriate legal framework, adapting the law and effective remedies, procedures and other programs.
- redress – introducing adequate and accessible judicial and non-judicial mechanisms for older persons in long-term care and in palliative care to complain and seek redress, applicable in all kind of settings.

D. Normative elements of autonomy and independence

Autonomy and independence for older persons should be framed both as a principle and a right.⁹

The **principle** should be enshrined in the preamble as follows:

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

Affirmation of the right:

Older persons have the right to personal autonomy and independence in relation to all aspects of their lives and to exercise that autonomy and independence in line with their will and preferences and on an equal basis with others.

⁹ The relevant international and regional documents do not present a clear and consistent picture in regard of a definition of autonomy and independence. These notions are not defined and often use them interchangeably, at least partially. Often language related explicitly to one of these values refers in the background to the other one.

Scope

Older persons have the right to enjoy legal capacity, which means both legal capacity and capacity for legal acts¹⁰, to make decisions, to determine life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. This includes the right to have those decisions respected.

The right to autonomy and independence for older persons includes individual, economic and financial and procedural aspects.¹¹

Individual aspects include:

- the freedom and capacity to make one's own decisions
- the ability to decide what one will eat or drink and the clothes one wears
- the choice of where and with whom one lives
- equal recognition before the law
- choosing one's own lifestyle
- self determination
- supported decision-making where necessary
- support and assistance
- will and preferences need to be respected.

Societal aspects include

- that communities and environments are age-sensitive and age-friendly
- participation in the community
- support the older person to participate
- that older persons are able to decide or act on their own will.

Economic and financial aspects include

- the ability to generate and receive income

¹⁰ The Polish legal system clearly distinguishes between legal capacity (Polish: zdolność prawna) and capacity for legal acts (Polish: zdolność do czynności prawnych). In line with the provisions of the Civil Code each and every human has legal capacity since birth. It is not possible to waive it, transfer it to another person or limit it in any way. This term means the capacity to be the subject of rights and duties. Each and every person with disabilities has legal capacity by law, on equal terms with other persons.

In turn, capacity for legal acts means the capacity to gain rights and duties on your own behalf, i.e. the capacity to shape your legal situation independently. In line with Article 11 of the Civil Code, full capacity for legal acts is gained upon coming of age, i.e. as a rule upon turning 18. Persons below 13 years of age and fully incapacitated persons have no capacity for legal acts.

There is a need to clearly specify in the new convention both aspects of the right, since in the Polish translation of CRPD only the legal capacity has been indicated and the capacity for legal acts has been omitted. In consequence in practice it poses a limitation of the enjoyment of the right for legal acts for persons with disabilities in Poland.

¹¹ Similar approach can be found in the Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, UN Doc, A/HRC/30/43.

- freedom to choose the type of work in which one engages
- freedom to spend one's money as one chooses
- access to and the right to choose types of support
- access to social security, health care, long term care and palliative care
- respect for one's will and preferences.

Procedural aspects include

- recognition as a rights holder
- support for decision-making if required
- the development and implementation of effective safeguards that ensure the autonomy of older persons to ensure respect for their rights, will and preferences and the avoidance of undue interference.
- the existence of an accessible and effective complaint mechanism if the will and preferences of an older person are not respected.

States shall take appropriate and effective measures:

- to ensure effective access to timely information on available support and services
- to ensure the enjoyment of the right without discrimination
- to ensure effective measures to assess and monitor the enjoyment of the right in practice.
- to provide training to formal and informal carers and volunteers on human rights including the rights to autonomy and independence.
- to ensure that the law on guardianship complies with the principle that the will and preferences of the person have to be respected and is not based on the principle of the "best interests of the older person".