UN Open Ended Working Group on Ageing

14th session

Normative Input

Focus Area: Right to health and access to health services

AGE Platform Europe

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www.age-platform.eu

This answer is submitted in reply to the call of the Chair of the Open-Ended Working Group on Ageing (OEWG) to non-governmental organisations. AGE Platform Europe (AGE) has ECOSOC status and is accredited to the OEWG since 2012.

On top of this contribution, please refer to the following documents :

- Substantive input on the right to health and access to health for the 13th session of the OEWG
- Policy Brief: Care must empower us throughout our lives
- Response to the European Commission Call for Evidence in view of the EU Care Strategy: "The EU Care Strategy must be built on supporting all human rights"
- Response to the European Commission Call for Evidence: a comprehensive approach to mental health

Definition

1. How is the human right of older persons to the highest attainable standard of physical and mental health defined in the national and local legislation in your country? If definitions are not available, how should such rights be defined considering relevant existing national, regional and international legal frameworks?

The right to health is enshrined in the European Social Charter[1] and the European Charter of Fundamental Rights[2]. In some member states, it is also enshrined in the constitution[3]. These are general provisions, although some member states also include references to older people in relation to the right to health in national constitutions. For example, the Spanish constitution refers to 'a system of social services that provides for their specific problems of health'[4] and the Polish Constitution provides for special health care for persons of advanced age[5]. The European Charter of Fundamental Rights (Art.35) provides for everyone's access to preventive health care and the right to benefit from medical treatment. The European Social Charter (Art.11) outlines general policy goals for states including, removing causes of ill-health, providing advisory and educational facilities for the promotion of health and preventing epidemic, endemic and other diseases and accidents. None of these instruments refers specifically to health from the perspective of ageing.

[1] Art. 11
[2] Art. 35
[3] Such as Spain, Poland, Italy and Portugal
[4] Section 50 of the Constitution of the Kingdom of Spain
[5] Article 68.3 of the Constitution of the Republic of Poland

A UN convention could enshrine a broad understanding of this right to include promotive, preventive, curative, rehabilitative, long-term and palliative care, covering both generalist and specialist treatment and taking into account specific challenges of old age. It would interpret health in light of the principle of equality and include a general obligation to eliminate systemic ageism, considered as a critical social determinant of health[6], to avoid age-based rationing, triage and other forms of differential treatment, but also exclusion from research and medical trials and insurance products. In addition to tackling ageism and its harmful health effects, a broad conception of the right to health for older persons would acknowledge and address other key social determinants of health[7] (income and social protection, food and nutrition, housing, environmental quality, etc.), which may play a critical role in shaping health outcomes and health inequities among older persons, often more so than access to healthcare and individual lifestyles choices. In this sense, for instance, the right to health would be linked to social protection and social assistance to guarantee the accessibility and affordability of health services. Moreover, the right to health would be based on autonomy and self-determination to make choices about options of treatment and care, ensuring that treatment is based on the free and informed consent of the person and aimed at the full participation of older persons in society. It would allow for targeted measures for specific health risks for older persons or when older people are disproportionately affected by certain conditions and to cater for disadvantaged groups. In line with the holistic view of health of the Alma-Ata Declaration and the Health for All agenda[8], the right to health for older persons should provide a framework for shifting the paradigm in health systems towards more person-centered integrated care approaches and for scaling up investment in preventive, primary health services responsive to the needs of older people[9] and supportive of their ageing well in place. Given the recent experience with the COVID-19 pandemic, this is also particularly important for empowering older people in their communities and building more resilient health systems. In general, a definition of the right to health should consider the profound societal transformations, including sociodemographic change, rapid urbanisation, digitalisation, climate and environmental crisis, and rising inequalities, posing increasingly complex challenges for health equity and the wellbeing of older populations worldwide. Particular attention should be also given to the impact of digitalization on older people's access to health care.

[6] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00524-9/fulltext
[7] https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1
[8] https://iris.who.int/bitstream/handle/10665/330291/WHO-UHC-IHS-2019.62-eng.pdf?sequence=1
[9] https://www.who.int/health-topics/ageing/transforming-health-and-social-services-towards-a-more-person-centred-and-integrated-care#tab=tab_1

2. The human right to health encompasses both access to health care and attention to the material and other conditions which are necessary for its full enjoyment. What provisions have been made to ensure that older persons enjoy access, on an equal basis with others, to social protection, adequate water and sanitation, adequate housing and to health education?

Principle 16 of the EU Pillar of Social Rights reads: "Everyone has the right to timely access to affordable, preventive and curative health care of good quality". UNECE ministers adopted the Rome declaration on MIPAA in 2022, putting active and healthy ageing, provision and access to long-term care on the agenda, however, this is not a legal provision. The EU has competence for health and safety in the workplace and has adopted a framework directive as well as more sectoral legal instruments. Other areas of legislative competence are patients' rights in cross-border healthcare, medicines and medical devices, cancer, tobacco and health promotion. However, health policies are by and large of national competence. Several soft texts have been adopted by EU member States, covering some of these aspects but in a non-comprehensive, fragmented and non-binding way.[10] These policy instruments do not distinguish between immediate/core obligations and progressive realisation, failing therefore to provide an adequate framework for the realisation of the right to health in old age.

Scope of the right

3. What are the key normative elements of the human right of older persons to the enjoyment of the highest attainable standard of physical and mental health? Please provide references to existing standards on elements including but not limited to:
   a) Prohibition of all forms of discrimination against older persons on the basis of age, alone or combined with other grounds, in all matters related to health.

Older people are often denied treatment (including life-saving treatment) or have access to fewer or poorer medical services on account of age, leading to unmet needs[11]. Older people are also excluded from health and life insurance, as well as

[10] Such as the Council recommendation on promoting health-enhancing physical activity across sectors of 26 November 2013; the Council recommendation on strengthening prevention through early detection: a new EU approach on cancer screening of 9 December 2022. Policy plans include the European Commission's Beating Cancer plan of 03 February 2021, Council conclusions on strengthening the European Health Union of 10 December 2021, Council conclusions on vaccination as one of the most effective tools for preventing disease and improving public health of December 2022 and several initiatives on eHealth.

[11] See https://www.age-platform.eu/covid-19-and-human-rights-concerns-for-older-persons/COVID and report on the UN Special Rapporteur on the rights of persons with disabilities

travel insurance covering health risks, which are subject to age limits[12]. Their needs are not taken into account in research and medical trials[13]. Prejudice lies at the root of discriminatory practices. For example, justifications of differential treatment may relate to the conception that being old equals being unhealthy, that older people's lives have less value or that there is not a lot that can be done to improve the quality of life of older people[14]. When symptoms are seen as a normal part of ageing, older people are not treated.

States have an obligation to provide healthcare to older persons without discrimination. They must eliminate ageism in law, policy and practice, and prohibit all forms of discrimination in the provision of health care, in health insurance, in medical trials and all other aspects of health, including on multiple grounds. States must guarantee that policies and programmes do not stigmatize older persons. In addition, they must address older people's specific health needs related directly or indirectly to age (e.g. Poverty, exclusion, digitalization, institutionalization, abuse and neglect). For example, older people may be subject to overmedicalization and/or use of (chemical or other) restraints[15]. States should also adopt measures to ensure support and reasonable accommodation so that older people can access mainstream services on an equal basis with others. Health systems must respond to the diversity of the older population and address multiple discrimination.

The existing legal framework allows for age limits and restrictions to the right to health. EU legislation does not cover age discrimination in access to health services and medical treatment. A few member states have expanded their legislation, but the majority only cover age discrimination in employment and occupation[16]. Art 11 of the European Social Charter can be read in combination with Art E on non-discrimination. The Committee of Ministers of the Council of Europe stated in its Recommendation (99)21 that age should only be taken into account as an aspect of the patient's general medical condition and a person's

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https://documents.un.org/doc/undoc/gen/n18/224/75/pdf/n1822475.pdf?token=g0Zj9i2MLj4fSBRiyy&fe=true (para 45)

[12] https://www.age-platform.eu/sites/default/files/AGE_IntergenerationalSolidarity_Position_on_Structural_Ageism2016.pdf

[13] https://www.age-platform.eu/sites/default/files/AGE_OEWG13_Contribution_Right_to_health.pdf

[14] See https://www.age-platform.eu/sites/default/files/AGE_IntergenerationalSolidarity_Position_on_Structural_Ageism2016.pdf where almost 40% of the people in Flanders were convinced that people beyond the age of 85 were not worthy of expensive medical treatment.

[15] https://ageing-equal.org/how-is-ageism-linked-to-inappropriate-medication-use/ and https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia and https://www.hrw.org/news/2022/09/19/chemical-restraints-deprive-older-people-liberty

[16] https://www.archive.equineteurope.org/How-are-Equality-Bodies-Fighting-Discrimination-on-the-Ground-of-Age

place on the waiting list should not be prejudiced because of age, unless it indicates a risk factor. But in practice, we see age-based distinctions are generally accepted as normal.

b) Provision of promotive, preventive, curative, rehabilitative and palliative health facilities, goods and services, as well as health care and support, including on aspects such as quality of care, long-term and palliative care and support.

The realisation of the right to health must encompass the full spectrum of promotive, preventive, curative, rehabilitative, palliative and long-term care and support. The continuity of services (e.g. between hospital and community-based care, between remote and presential treatment, etc) must be guaranteed through the availability of a range of options that the individual can choose from on the basis of free and informed consent. Health services should include both generalised and specialised services (e.g. geriatric care) spanning all health facilities available to the public, including -among others- services for sexual health. Older people should also have access to support and assistive devices that are essential for the equal realisation of the right to health. The definition of the right for older people would help to reorient health and social services towards a more person-centred and coordinated model of care. State obligations extend to guaranteeing the underlying determinants of health, which include food and nutrition, housing, safe water, adequate sanitation, safe and healthy working conditions, and a healthy environment. Information, awareness-raising and health literacy are integral aspects of States' obligations in the context of health care.

c) Availability, accessibility, acceptability and quality of health facilities, goods and services as well as health care and support, including aspects such as quality of care, long-term and palliative care and support.

The health care system (including preventative, rehabilitation, long-term and palliative care) must be accessible to everyone regardless of age. States must ensure that costs do not put an excessive burden on individuals, by ensuring universal health coverage in social protection, in line with international obligations. States must adopt positive measures when necessary, for example for disadvantaged groups. Age limits or age-based rationing in the allocation of services and benefits (e.g. disability allowance, access to rehabilitation, cancer prevention or surgical treatment) must be prohibited. Laws must be extended to prohibit age discrimination in access to health and life insurance, as age limits, low coverage and disproportionate premiums or out-of pocket payments limit older people's equal access to health services.

States must ensure that the provision of health is not subject to long waiting lists, that older people's needs are not deprioritised and that the number of health care professionals and equipment is adequate to meet the needs of the population. States must ensure the physical accessibility of buildings, equipments and services, as well as the availability of services for remote or marginalised locations and groups. They must provide adequate support for individuals who need it (e.g. Adequate public transport, remote consultation, language support, reasonable accommodation, etc). Information and signage must be accessible and available to everyone, including through non-digital means. States must ensure that telemedicine shall not become an obligation for patients and alternative ways of interacting with medical staff shall always be made available. Provision of health services must also cover monitoring of quality and support and redress for victims of abuse. Quality working conditions for formal and informal carers are closely correlated with the quality of care provided and lowers the risk of abuse and neglect in care settings, therefore Member States must ensure sustainable working conditions, adequate training and support.

Moreover, to ensure health equity, it is the States' responsibility to ensure availability of health services across its territory. As such, the legal framework should promote measures to address shortages and uneven spatial distribution of health and social care staff, underserved areas or 'Medical Desserts', which is a growing issue affecting older persons in Europe and many health systems worldwide.[17],[18]

c) Exercise of older persons' legal capacity on an equal basis with others, including the ability to make an informed consent, decisions and choices about their treatment and care.

Older persons are sometimes denied legal capacity and/or informed consent in access to health, long-term and palliative care, particularly when they are perceived as having cognitive health issues. This has been largely justified because it is considered as necessary or in the best interests of the person.[19] They may also be pressured into signing assisted dying or do not resuscitate agreements, due to prejudice, cultural or family expectations and lack of support. Laws and policies must be revised to not allow for such practices to continue. States must put in place stronger means of legal protection and mechanisms that allow for supported decision-making. This involves information for patients as well as training and anti-ageism awareness among health and care professionals. Families and caregivers must not be allowed to provide consent on behalf of older persons. Involuntary treatment and placement as well as the use

[17] https://epha.org/medical-deserts-a-growing-problem-across-europe/
[18] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10590222/
[19] See CoE recommendation: https://rm.coe.int/1680695bce para 55-62

of other forms of coercion (e.g. undue influence, digital pills and psychotopic drugs[20]) must be prohibited.

e) Access to prompt and effective remedies and redress when older persons' right to health is violated.

Under-reporting of human rights abuses is quite common due to internalized and systemic ageism, lack of information and rights awareness, inaccessibility of procedures, financial and emotional cost and lack of support. Legal and non-judicial remedies must be easily accessible and adequate support to victims guaranteed. In the context of care, rights violations often coincide with a relationship of dependency (on care, on emotional support, on social interactions). Therefore, reporting and remedy mechanisms must be made known and must be independent of care providers.

State obligations

4. What are the measures that should be undertaken by the State to respect, protect and fulfil the human right of older persons to the highest attainable standard of physical and mental health, regarding the normative elements as provided above?

(a) Remove all legal and policy barriers that prevent older people from accessing health-related information, goods and services on an equal basis with others;

(b) Abolish laws and practices that allow for coercive treatment of older persons in health, long-term and palliative care settings;

(c) Mainstream the rights and needs of older persons in all health services and programmes and ensure access to adequate primary health care as well as specialized (e.g. geriatric) services;

(d) Ensure that healthcare (including promotive, preventive, curative, rehabilitative and palliative health facilities, goods and services), is available, accessible, adequate and affordable for all older persons;

(e) Guarantee that care services are based on free and informed consent respect privacy and do not lead to neglect, abuse or maltreatment;

(f) Improve health literacy and ensure access to adequate information and support among older people;

(h) Implement awareness-raising campaigns and training programmes for health-care professionals to change their perceptions regarding older persons

[20] https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia

and provide guidance on how to provide inclusive services and avoid abuse and neglect;

(i) Ensure effective and independent monitoring to prevent all forms of exploitation, violence and abuse;

(j) Actively involve and consult with older persons and their representative organizations in the design and implementation of health-related legislation, policies and programmes;

(k) Collect adequate disaggregated data on the health status and the access to health care of older persons;

(l) Ensure that scientific research and medical trials include older persons;

(m) Provide adequate geriatric training to health, long-term care and palliative care professionals and appropriate support and respite for informal caregivers;

(n) Reaffirm the commitment towards developing integrated health systems based on policies and investment in primary health care;

o) Implement policies to address health inequalities and key social determinants of health related to the effective promotion and protection of other related human rights, which are crucial for the enjoyment of health.

Special considerations

5. What special measures and specific considerations should be considered in developing the normative content on older persons' right to health?

Realising the right to health in old age should not lead to the medicalization of ageing. Traditionally, older people were seen as suffering from cognitive and physical decline, which has led to the prevalence of a medical model of ageing. While some functional decline can be expected in old age, states must recognize that ageing does not affect individuals in a uniform way and to acknowledge how physical and social barriers can create health risks or aggravate existing conditions. In particular, states must take action to address the impact of systemic ageism on health, as indicated by the WHO[21].

6. How should the responsibilities of non-State parties such as private sector be defined in the context of the human right to health of older persons?

[21] Global Report on Ageism (2021): https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combatting-ageism/global-report-on-ageism

The obligation of States to eliminate ageism and age discrimination must extend to private actors offering health-related services. Non-state services and products must be accessible, affordable and equally available regardless of age. States should monitor the delivery of health services by private actors and prevent abuse and neglect (e.g. Awareness-raising and training for professionals). States must offer redress and support for victims in cases of breaches by private sector providers.

About AGE Platform Europe

AGE Platform Europe is the largest European network of non-profit organizations of and for older people. We elevate older people's voice, bringing their experience and aspirations to the table to celebrate ageing and fight for equality at all ages.

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