

# 13<sup>th</sup> session of the United Nations Open-Ended Working Group (2023) AGE Platform Europe submission on the Right to Health and Access to Health Services

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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.

As the largest European network of self-advocacy organisations of older people, our position aims to reflect the situation at EU level on behalf of the 40 million older citizens represented by our members. Our contribution is based on written answers received from organisations of older people in several EU Member States and webinars open to all AGE members.

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## National legal and policy framework

1. What are the legal provisions and policy frameworks in your country that guarantee the right of older persons to the enjoyment of the highest attainable standard of physical and mental health, including access to promotive, preventive, curative, rehabilitative and palliative health facilities, goods and services?

The right to health is enshrined in the European Social Charter<sup>1</sup>, the European Charter of Fundamental Rights<sup>2</sup> and the European Pillar of Social Rights<sup>3</sup>. In some member states, it is also enshrined in the constitution<sup>4</sup>. UNECE ministers adopted <u>the Rome declaration</u> on MIPAA in 2022 putting active and healthy ageing, provision and access to long-term care on the agenda, although 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 aspirational texts have been adopted by EU member States.<sup>5</sup>

2. What steps have been taken to ensure that every older person has access to affordable and good quality health care and services in older age without discrimination?

Overall, AGE members state that health care is generally affordable and of quality for all those who have access to health insurance and care, with exceptions outlined below and in Q6.<sup>6</sup> Mandatory public health insurances cover most persons fairly well, as long as they are employees. Self-employed sometimes have the choice to be part of the public health

<sup>&</sup>lt;sup>1</sup> Art. 11

<sup>&</sup>lt;sup>2</sup> Art. 35 – right to health care including preventive health care and a general policy aim of a high level of health protection

<sup>&</sup>lt;sup>3</sup> Principle 16 on health care, alongside principle 10 on healthy work environments.

<sup>&</sup>lt;sup>4</sup> Such as Poland, Portugal

<sup>&</sup>lt;sup>5</sup> Such as <u>the Council recommendation on promoting health-enhancing physical activity across sectors</u> of 26 November 2013; <u>the Council recommendation on strengthening prevention through early detection: a new EU</u> <u>approach on cancer screening</u> of 9 December 2022. Policy plans include the European <u>Commission's Beating</u> <u>Cancer plan</u> of 03 February 2021, <u>Council conclusions on strengthening the European Health Union</u> of 10 December 2021, <u>Council conclusions on vaccination as one of the most effective tools for preventing disease</u> <u>and improving public health</u> of December 2022 and several initiatives on eHealth.

<sup>&</sup>lt;sup>6</sup> A specificity of the German statutory health insurance should be mentioned: when people are uninsured and join the statutory health insurance, they have to pay 'insurance premium debt' for up to four years of the time where they were not insured, creating a very high financial barrier for joining the health insurance. Uninsured are for example undocumented migrants or homeless

insurance or not, leading to some exclusion for them. All persons, insured or not, have access to emergency care in principle.

To access parts of the health system, it is sometimes necessary to take out private insurance to have access to quality care, although insurance is more expensive to older persons.<sup>7</sup> In several Member States the complexity of competences for health between levels of government is an issue that can lead to the fragmentation of care.<sup>8</sup>

Affordability is an issue for some groups<sup>9</sup> especially where the public health system creates long waiting times, so that patients need to rely on expensive private care. Access to medicines can be expensive as well and not covered sufficiently by insurance<sup>10</sup>. Affordability is a great issue regarding long-term care in many Member States.<sup>11</sup> Some statutory care insurances only provide for flat-rate interventions, leaving higher costs for higher care needs with the person in need for care or their family. Lack of affordability means that older people in need for care stay home and require informal care.

In some places, access to care is impeded by geographical barriers: emergency care in France is an issue<sup>12</sup>, while in Poland, inadequate public transport limits access to specialist care in less urbanised areas.<sup>13</sup>

AGE members observe overall that there should be stronger policies for prevention, with the notable exception of vaccination against COVID-19 and influenza. In Poland, a programme called 'Prevention 40+' provides good incentives to perform medical check-ups.

AGE members point out the inadequacy of specialist care and especially geriatrics; in Poland, there are very long waiting times for rehabilitation. In the area of long-term care, there is a glaring inadequacy of services available, on top of the issue of affordability. Palliative care is also insufficient in many Member States<sup>14</sup> and more resources should be put in improving mental health<sup>15</sup>.

Another frequent issue pointed out by AGE members is the fragmentation of care, such as between community-based care and hospital care.

<sup>&</sup>lt;sup>7</sup> This applies for example to hospital insurance in Belgium, or dental insurance in many Member States

<sup>&</sup>lt;sup>8</sup> AGE members referred to Belgium and Poland

<sup>&</sup>lt;sup>9</sup> See Question 6

<sup>&</sup>lt;sup>10</sup> Mentioned for Portugal and Poland. In Poland, there is an interesting exemption of payments for some medicines for persons over 75, however, this only concerns some common drugs used to treat diseases that are more common among older persons.

<sup>&</sup>lt;sup>11</sup> For example, In Belgium, the average private sector pension is 1,200€, and residential care costs between 1,800€ and 2,000€

<sup>&</sup>lt;sup>12</sup> Pointed out especially for rural areas, but members also underlined that it takes long in urban areas as well.

<sup>&</sup>lt;sup>13</sup> French members also outline the existence of 'medical deserts', where both generalist and specialist care becomes geographically inaccessible.

<sup>&</sup>lt;sup>14</sup> Observed in France and Poland

<sup>&</sup>lt;sup>15</sup> Cf. AGE's contribution to the European Commissions call for evidence on mental health

3. What data and research are available regarding older persons' right to health and access to health care and services? Please indicate how national or sub-national data is disaggregated by sex, age and inequality dimensions, and what indicators are used to monitor the full realization of the right to health of older persons.

AGE members point out that data about health status is not sufficient and not clearly systematised. Medical trials, which are used to assess the usefulness and risk of a certain treatment, still do not necessarily integrate persons above a certain age, although there is a higher proportion of older persons undergoing medical treatment.<sup>16</sup>

There is more information about the human resources available for long-term care, but not whether these resources are adequate.

4. What steps have been taken to provide appropriate training for legislators, policymakers, health and care personnel on the right to health of older persons?

While health care staff are in general well-trained across Europe, there are important shortcomings in some sectors. For example, geriatrics is not widely integrated into training of generalists and geriatric specialists are lacking. Training curricula for long care professionals might lack elements on the prevention of abuse and neglect, as well as the rights of persons in need for care. Finally, there is not enough training and support to informal carers across the EU.

In Portugal, while staff is well-trained, working conditions are unsustainable, and the sector has a strong turnover of staff. In Eastern European countries, AGE members point out that as soon as health staff are well trained, they are quite likely to be recruited in Western European countries, creating an issue of brain drain. Caritas Romania has an apprenticeship programme with Caritas Switzerland to reduce this brain drain.

<sup>&</sup>lt;sup>16</sup> See for example <u>WHO World Report on Ageing and Health</u> (2015), p. 114: 'Specifically, more research is needed that looks at how commonly prescribed medications affect people with multimorbidity, which is a departure from the typical default assumption that the optimal treatment of some- one with more than one health issue is to add together different interventions (158). And out- comes need to be considered not only in terms of disease markers but also in terms of intrinsic capacity. Improved postmarketing surveillance can help fill this gap until new approaches to clinical trials that are more relevant to older age have been developed.'

#### Progressive realization and the use of maximum available resources

5. What steps have been taken to align macroeconomic policies and measures with international human rights law, to use maximum available resources for the realization of older persons' right to health, such as through expanding fiscal space, adopting targeted measures and international cooperation?

In the EU, the economic and fiscal framework in principle restricts public debt and budgetary deficits, which has led in the past to austerity policies that restricted investment in health and reduced availability and affordability of health services, for example in Greece. A prepandemic report<sup>17</sup> evaluated the lack of investment into social infrastructure at 170 billion Euro annually, with care forming a large part of this investment gap. These rules are currently on hold but remain part of the EU's legal framework.<sup>18</sup> The suspension of budgetary rules during the pandemic allowed the purchase of medical

equipment, conducting tests on a massive scale and fund the development, production and roll-out of the EU's vaccination strategy.

Across the EU, there is a terrible issue of staff shortages and people who are active in the health sector are overburdened. In France and Portugal, new laws strengthening human resources are planned, but are delayed. Shortages are significant in long-term care, but also in medical care, such as doctors and nurses, with Poland having one of the lowest ratios<sup>19</sup>. Shortages are more pronounced in rural areas. This leads to long waiting times, especially to access specialist care.<sup>20</sup> The pandemic has shown that salaries and working conditions in the care sector were unsustainable. In France, salaries were raised, but staff shortages persist.

Beyond human resources, a lack of available care services is widespread and aggravated because of increasing health and care needs due to demographic change. In Poland, public

<sup>&</sup>lt;sup>17</sup> <u>High-Level Task Force on Investing in Social Infrastructure in Europe, Boosting investment in social infrastructure in Europe, 2018.</u>

<sup>&</sup>lt;sup>18</sup> During the COVID-19 pandemic, the European Union triggered the 'General Escape Clause', allowing deviation from the objectives of 60% GDP of public debt and 3% GDP of yearly deficit for each member State and introduced, for the first time, large EU-level funds financed both by Member State contributions and EU-level debt to mitigate the economic effects of the pandemic. The General Escape Clause remains activated until 2024 for the time being. This situation has shown the inadequacy of the EU-level fiscal framework to provide for the guarantee of the right to health. Currently, a reflection is ongoing about the reform of the economic governance framework.

<sup>&</sup>lt;sup>19</sup> 3.3 doctors and 5.1 nurses per 1,000 persons in 2020; hospital care in the Netherlands also seems to be an issue

<sup>&</sup>lt;sup>20</sup> For example, in Poland, one has to wait 200 days for a cataract surgery, 300 days for a hip replacement, 400 days for knee replacement

spending on health is low<sup>21</sup> and in particular spending on long-term care and prevention is insufficient. As a result, while periodic screening and geriatric assessments of older persons would be possible, there are not enough resources to make them available.

Across the EU, the pandemic has laid bare shortcomings and the need for investment. Several policy plans have been announced, such as the <u>EU Care Strategy</u> on EU and national level, but they still need to materialise.

The privatisation of care in some member States<sup>22</sup> creates additional financial barriers.

# Equality and non-discrimination

6. What are the challenges faced by older persons in their enjoyment of the right to health, including the impact of intersectional discrimination and inequality based on age, gender, disability and other grounds?

Ageism in the health system leads sometimes to the under-diagnosis of diseases, as symptoms can be discarded as purposedly being part of the 'natural' ageing process. Ageism also leads to less expensive treatment being favoured for older perosns.

There are examples of age limits to access certain treatments in the EU, in the absence of a general framework for equal treatment. For instance, access to cancer screening is often restricted to persons until a certain age, although risks continue to increase.<sup>23</sup> The lack of coordination of health providers is a form of age-related discrimination, as older persons have a higher risk of multiple health conditions – if specialists do not coordinate on treatment and in the absence of geriatric assessments, the risk of overmedication, secondary effects and interactions between different treatments are high. Similarly, the lack of resources in long-term care can be traced back to structural ageism.

Intersectionality issues arise in the access to health insurance on various grounds. In many Member States<sup>24</sup>, homeless are excluded from health insurance; this also applies to undocumented migrants<sup>25</sup>, asylum-seekers and prisoners<sup>26</sup>. Stigma around mental health limits patients' possibilities to seek care. The urban/rural divide lead to discrimination in the access to health services for persons in rural areas.<sup>27</sup> As prevention policies are set on the regional and local level in Poland, there are inequalities in the access to preventive health.

 $<sup>^{\</sup>rm 21}$  6.5 % of GDP

<sup>&</sup>lt;sup>22</sup> The Netherlands

<sup>&</sup>lt;sup>23</sup> Age limits for cancer screenings exist in the Netherlands, Sweden, Portugal, Poland and France

<sup>&</sup>lt;sup>24</sup> including Belgium and Poland

<sup>&</sup>lt;sup>25</sup> Observerd in Belgium

<sup>&</sup>lt;sup>26</sup> Observed in Germany

<sup>&</sup>lt;sup>27</sup> Observed in France, Belgium, Germany and Poland

There is discrimination based on the type of disease that one older patient has. For instance, palliative care in Poland is accessible only for persons within a certain list of diseases, rather than based on actual need – older persons with intellectual disabilities have therefore no access to palliative care. Similarly, in some Member States, there are different systems for older and younger persons with disabilities, leading to different services, funding and options. Members in Poland report that 38 % of persons between 85 and 89 face physical barriers to leave their homes, reducing their ability to access care. Members report that older women are less likely to access breast reconstruction and more likely to be treated by mastectomy.<sup>28</sup> Digitalisation creates a barrier for older persons who are digitally excluded, reducing their access to services, particularly since the roll-out of telemedicine services during the COVID-19 pandemic.<sup>29</sup>

Health status itself is a source of discrimination: for instance, you have to undergo medical check-ups for getting a mortgage loan past a certain age in France.

Life-long disadvantages have an impact on older persons' health status, an effect which has an especially detrimental effect on women, Roma or other minorities, persons with low educational achievement, long or strenuous working lives, or older migrants.

7. What measures have been taken to eliminate ageism and discrimination based on age, including discriminatory laws, policies, practices, social norms and stereotypes that perpetuate health inequalities among older persons and prevent older persons from enjoying their right to health?

The lack of a horizontal equal treatment framework on EU level including access to health services allows for continued discrimination.

As ageism leads to the lack of important policies regarding health promotion, prevention, support for informal carers or fight against loneliness, often older persons' organisations take action. For example, in Poland, a lot of health promotion is made by civil society organisations, especially by about 700 Universities of the Third Age.

<sup>&</sup>lt;sup>28</sup> Reported from Germany

<sup>&</sup>lt;sup>29</sup> German member BAGSO reports that health and long-term care are the areas where older persons experience most problems to have 'offline access'

8. What measures have been taken to ensure that older persons are able to exercise their legal capacity on an equal basis with others, including making an informed consent, decisions and choices about their treatment and care?

AGE members point out that there is a lack of information provided to older persons on the options, treatments, interaction of treatments, making informed consent to a specific treatment difficult. Patronising behaviour, such as 'elderspeak' by health professionals contribute to the barrier to complete information. Decisions are often made without the direct inclusion of the patient – especially for older people. There is a lack of awareness of the rights of people receiving care. This general culture leads to the risk of disrespecting older persons' choices.

In Poland, a Law on Older Persons grants them the right to comprehensive and clear information about their state of health, diagnosis, and regulates how consent to treatment is expressed. In Germany, persons in need for care have access to individual 'care advisors', a practice that should be extended to the period before one develops a care need.

Some Member States<sup>30</sup> have no specific law on legal capacity that is adequate to the situation of older persons. Procedures to deprive persons of their legal capacity are not always helpful and can be used to force older persons to undergo a certain treatment, particularly for persons with cognitive or intellectual disabilities.<sup>31</sup> In some Member States, an instrument supporting a person with intellectual disability in making informed decisions, such as advance directives and enduring power of attorney, is lacking.

## Accountability

9. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for the denial of their right to health?

Older persons seek to complain and redress by organisations in which they have trust. Logically, trust is not placed in care providers who are seen as committing abuse or neglect, even if complaints procedures exist – such as specific commissions in hospitals in France or Poland. Older persons rather turn to the public insurance system (Poland) or health insurers (Belgium). In Poland, there is a specific patients' rights ombudsperson and the Commissioner for Human Rights is seen as reacting fast and effectively on complaints. The Commissioner

<sup>&</sup>lt;sup>30</sup> Mentioned for France

<sup>&</sup>lt;sup>31</sup> As an illustration, decisions can be taken in Poland by a legal guardian, appointed by the court in an incapacitation procedure. In some cases, the refusal of treatment by older persons is sufficient for a doctor to ask the family for an incapacitation procedure. The Human Rights Commissioner called for changes in the legal system and calls it out as being discriminatory.

also seizes itself for cases that emerge in the media. In Portugal, it is perceived that the reporting system is only effective for extremely serious cases.

10. What mechanisms are in place to ensure the effective and meaningful participation of older persons living in different geographic areas of the country in the planning, design, implementation and evaluation of health laws, policies, programmes and services that affect them?

Older persons' organisations do not seem to routinely be consulted on health policies. In France, organisations are complaining about medical deserts (areas with no sufficient coverage of health services), but policy response to this is not sufficient. In Germany, patients' organisations are given a statutory advisory role in long-term care policies. The picture is different in some Member States on local level: in Poland, there are over 400 older persons' councils who advise on local decisions, contributing to better prevention, health promotion and social inclusions.



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