

The right to autonomy, health and independent living

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Nena GEORGANTZI

Legal & Research Officer - AGE Platform Europe¹

While it is impossible to be exhaustive regarding a topic that encompasses so many different facets, this intervention will focus on questions of autonomy and health in relation to different care settings. In the long-term and health care older persons may entail serious human rights violations stemming from a poor care path and the disregard of the dignity of the older person often due to age discrimination and the so-perceived inevitable destiny of old age.

Therefore this presentation discusses two main topics: the exacerbation of human rights shortcomings due to austerity and limited resources and the (in)adequacy of the existing human rights framework to respond to the challenges older people face today.

Which are the issues at stake?

First, we need to guarantee that older persons are not forced against their will to enter in any type of care setting, whether in a residential or home care. Besides forced institutionalisation, which is in itself a concerning phenomenon, a recent practice that threatens the rights of older persons is encountered in countries hit by the crisis. For example in Spain² many older persons have been withdrawn to informal care at home because their families can no longer afford to cover the expenses of residential care, which exposes them to risks such as inadequate care, abuse and limited autonomy as this is not done with prior assessment of their needs.

In care delivery, older people often don't have a say on what to eat, what to wear, what time to go to bed or even whether to use the bathroom. Caregivers sometimes carry out even the most intimate tasks, without discussing the older person's preferences. Older persons may have no control of the visits they receive and can even be forced to stay in bed for long periods of time. These situations do not occur in residential settings alone, as care at home, delivered by a wide range of providers, entails equal if not greater risks of human rights violations. According to an EU survey carried out in 2009, 85% of the respondents agreed that frail elderly people could not live autonomously because their homes were not adapted to their needs.

As a result, respecting the wish of older people to remain at home requires also good quality home care and an enabling environment.

Health care which is instrumental to prevent deterioration – and to restore as far as possible –the health, wellbeing and the capacity to live independently,

¹ AGE Platform Europe is a European network of more than 160 organizations of and for people aged 50+ representing directly over 30 million older people across in Europe. AGE aims at voicing and promoting the interests of the 150 million inhabitants aged 50+ in the European Union and at raising awareness of the issues that concern them most.

² <http://www.rtve.es/alacarta/videos/telediario/crisis-economica-afecta-cada-vez-mas-residencias-mayores/1432350/>

is largely undervalued by society. Older people have a higher risk than other patients groups to be under-treated for pain or not be interventions that improve quality of life and autonomy (such as hip operations), while over-prescription of drugs may also seriously affect their lives. In addition, in most European countries there are age limits in preventive care, such as free breast cancer screening, which for instance in Belgium is available only to women 50-69 years old³.

Nevertheless, maintaining health into old age requires investments during the entire life span, but also providing high quality curative, rehabilitative and preventive care in advanced age.

The impact of limited resources and austerity measures

In most EU countries, the care sector has long been suffering from lack of resources, due to the combination of growing numbers of care recipients and staff shortage. The crisis has further amplified the problem and evidence from grass root level points out to general shortages in care provision, shrinking quality of services as well as decrease of informal care within family.

In Greece, many older people renounce health care services because they cannot afford them, as they are asked to pay the full cost of all their medication and care aids, as well as an increasing patient fee, although severe cuts were imposed even on low pensions.

Additionally, the trend to re-individualise part of health and dependency risks is very alarming and may lead to more inequalities as complementary health insurance is often too expensive for older people, especially older women who are more affected by poverty.

The Netherlands is an illustrative example of this situation, as the Dutch report for the implementation of the Madrid International Plan of Action on Ageing (MIPAA)⁴ affirms: *“The care system is under pressure. Costs are rising and staff shortfalls are growing... Individual patients must be able to exercise their rights but, at the same time, there need to be guarantees that the fulfillment of individual rights will be reasonable and fair”*. AGE Platform Europe members have shared information according to which the Dutch minister of Health announced that the government is considering a policy under which not only situations that cause a minor discomfort, but also more serious conditions will not be covered by public health insurance⁵, something obviously adversely affecting older persons as the majority of annual health care costs are made by people over the age of 65.

As a result, changing demographics combined with the pressure on public budgets are increasing the risk of human rights violations against older persons in many EU countries. If we don't shift the discussion from economy and needs to rights, states will fail to guarantee high standards of health and autonomy; instead our societies - tormented by the current economic climate -

³ For further information: http://www.age-platform.eu/images/stories/EN/pdf_AGE_recommendations_to_tackle_the_issue_of_age_limits_in_breast_cancer_screening_Final-2.pdf

⁴ http://www.unece.org/fileadmin/DAM/pau/age/country_rpts/NLD_report.pdf

⁵ <http://www.zorgvisie.nl/Financien/14198/Schippers-wil-toch-bezuinigen-op-lage-ziectelast.htm>

will limit themselves to a *'reasonable fulfillment of rights'*, with an inherent risk of eroding the inviolable and universal character of human rights.

The existing legal framework

Respect for autonomy forms part many human rights instruments and is also one of the transversal principles of the Convention on the Rights of Persons with Disabilities. In certain cases neglect is so severe or coercive measures and physical restraints are used that it can amount to inhuman and degrading treatment, contravening various regional and international documents. Provisions on the right to health, dignity and equality are also relevant.

At the EU level the European Charter of Fundamental Rights declares the rights of the elderly to live a life of dignity and independence, but in practice care and autonomy are national matters and unfortunately the EU Charter has limited power as it does not confer any competences to the EU to act to protect older persons and prevent human rights violations. For the EU Fundamental Rights Agency the rights of older persons are still invisible and even in two recent publications on the rights of persons with mental disabilities, older persons were not considered nor interviewed in the survey, thus limiting understanding of the needs of this target group.

The European Convention of Human Rights does not make specific reference to age, nevertheless the caselaw of the European Court of Human Rights can be helpful in giving content to the human rights of older persons. This of course implies expecting a case to reach the court and asking from vulnerable victims to bear the risks and costs of long and complex litigation, while in reality many barriers exist. Besides, it is highly unlikely that a Convention where older persons' rights are intangible will be able not only to offer redress (which is the objective of litigation) but also prevent violation of rights. The lack of sufficient protection is also reflected in the decision of the Council of Europe to draft a non-binding instrument on the rights of older persons⁶.

One of the most relevant legal instruments is undoubtedly the UN Convention on the Rights of Persons with Disabilities (CRPD), which has achieved to codify a paradigm shift in terms of autonomy, legal capacity and decision-making. While older people with functional limitations or high support needs should meet the definition of disability, not all of them see themselves as disabled persons and neither do EU states. This means that there are important protection gaps arising on the one hand from the fact that the intersection of age and disability is not taken into account by EU legislators and policymakers and on the other hand because is a distinction on the treatment of people with impairments depending on their age.

This is the case for example in France, where the allowance for the disabled under the age of 60 is twice as generous as the Allocation Personnalisée d'Autonomie (APA) benefit granted to people over the age of 60. Moreover for the former benefit there is no user fee, whereas the APA beneficiaries contribute to long-term care costs up to 90% depending on their income. Disparities in the two schemes arise from the conceptualisation of the notion of dependency in old age in French law – and in my knowledge also in other

⁶ http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/default_EN.asp

European legal systems, like in England and Belgium– is perceived as a predictable, if not inevitable condition, unlike disability which is seen as an unpredictable limited capacity to act. Although a 2005 law called for the abolition of this age barrier, this is still not the case and of course financial considerations are impeding any progress. So, under the current French system, a country which ratified the CRPD, people have an interest to become incapacitated before the age of 60, because at 60 years old and a day, one is considered just an older person and not a human being with rights equal to others. So neither the CRPD offers equal and adequate protection to older persons.

The protection of older people's rights by EU member states is inconsistent and national standards on the rights of older people vary, depending on whether there is domestic caselaw on this field, whether there are standards in provision of care, etc. Although of course this merits further studying, an illustrative example comes from the United Kingdom where according to caselaw⁷ home care provided by the private and voluntary sector is not covered by the Human Rights Act and there is thus a legal gap between legal protection in residential and home care. Besides, in another case⁸ an older woman who suffered from reduced mobility due to a stroke, was forced against her wishes, to use incontinence pads and absorbent sheets at night. According to the Court of Appeal the local authority was entitled to reduce the care package in the context of limited resources, even though it meant in practice limiting the autonomy of the older adult which can also be considered an inhuman and degrading treatment, as well as a deterioration of the quality of life and health of the person in question.

Is there a need for a human rights approach?

First, restrictions of autonomy in later life are not linked with pathological decline but are associated to how society treats older people: like non-productive human beings, like they don't deserve health care since health decline is a normal part of ageing and older people will sooner or later become senile. Overall, loss of autonomy is very much linked with perceptions of ageing and environmental factors so we need to move towards a social model of ageing.

In fact, although existing human rights standards should apply to older people as to other age groups, if there's a lack of or superficial understanding of the human rights obligations among the different stakeholders involved in the chain of care there is an important risk of undermining the rights of older persons. This is also highlighted in some of the EU countries reports on the MIPAA. For example, the Dutch report⁹ refers to the need for a specific act for residential care setting out concrete rights of residents, '*such as the right to a daily shower and to spend some time each day in the open air if they so wish*'. So, even the most obvious individual rights become invisible with age.

In Spain where a [Law on the Promotion of Personal Autonomy and Care for Dependent Persons](#), was adopted – according to the authors of the national

⁷ YL v Birmingham City Council and Others (2007) UKHL 27

⁸ R (McDonald) v Royal Borough of Kensington and Chelsea (2010) EWCA Civ 1109

⁹ http://www.unece.org/fileadmin/DAM/pau/age/country_rpts/NLD_report.pdf

report¹⁰ – this piece of legislation *‘has been instrumental in achieving a deep reform regarding the attention to dependent persons in Spain and has created a new subjective right which reinforces all social rights and the social protection system in general while dependency is now in the realm of the public agenda, whereas before it was considered a personal or family problem’*.

It is exactly these considerations – visibility, specificity, implementation guidance, clarity and data generation – which arose the need for a specific instrument on the rights of people with disabilities. I don’t see why States would renounce the same level of protection to older persons.

Conclusions

To conclude, as long as older persons are not seen as holders of specific rights, there is a risk that only the most perfunctory level of care will be provided to older persons. An international human rights instrument would enhance public awareness on the rights of older persons in terms of autonomy and independent living, promote a social model of ageing and strengthen visibility of older people as rights holders. It would moreover close loopholes in the existing legal framework and give Member States a concrete obligation to respect, protect and fulfill these rights. Last it would act as a catalyst for age-appropriate policies, ensuring that there are no discrepancies in the understanding and enforcement of older persons’ rights.

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¹⁰ http://www.unece.org/fileadmin/DAM/pau/age/country_rpts/ESP_report.pdf