



20th April 2018

## Questions on Autonomy and Independence

### AGE Platform Europe input

This short answer is submitted in reply to the call of the Chair of the Open-Ended Working Group on Ageing (OEWG) to NGOs. 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 and to provide a comparative overview of the EU Member States 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, oral debate in the frame of our Council of Administration where representatives from 24 countries<sup>1</sup> and 6 European organisations/federations<sup>2</sup> sit as well as reflections shared during an expert seminar on the human rights of older persons co-organised by AGE and desk research using sources referenced in this document.

Separate answers covering normative elements on freedom from violence, abuse and neglect and equality and non-discrimination, as well as questions on autonomy & independence are also submitted.

Further resources:

- [Older persons' self-advocacy handbook](#)

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<sup>1</sup> All EU countries with the exception of Croatia, Latvia, Luxembourg and Slovakia

<sup>2</sup> FIAPA, ESU, NOPO, EURAG, EDE, OWN Europe



## Question 1

- There is inconsistent understanding and standards around older people's autonomy and independence in the European region and often this is limited to situations of ill-health and impairment<sup>3</sup>.
- Several texts foresee restrictions to autonomy and provide for measures to allow older people to live independently in the community only "for as long as possible". Under regional standards the institutionalisation of older people is permissible. These limitations entail a narrower definition of these rights in the context of old age than in disability.
- Only the Council of Europe CM(2014)2 recommendation recognizes explicitly older people the right to legal capacity on an equal basis with others, but this is a non-binding instrument.
- National constitutions lack specific references to older people's autonomy and independence, but older people are indirectly covered by general provisions (where those exist). In the few cases where secondary national law refers to autonomy and independence in old age, these are primarily related to health and care law or mental capacity acts.
- As a result, there is no comprehensive and consistent definition of autonomy and independence for all older persons, regardless of whether they face impairments or chronic illness, in all spheres of life (including, inter alia, financial independence, employment, education, end of life) and without limitations.

## Question 2

The exercise of these rights presupposes equality before the law and legal capacity. It is also dependent on the prohibition of discrimination, which is essential to overcome age-based restrictions to autonomy and independence. In order to live independently some older people may require support (including inter alia long-term care, supported decision-making, etc)<sup>4</sup>, need social protection to be able to enjoy an adequate standard of living (adequate income), adequate housing and securing the right to work and access to health care (including prevention and rehabilitation). Particularly relevant are also the rights of protection from violence, abuse, neglect and exploitation, accessibility, education and training, access to information and access to justice.

## Question 3

- The persistence of ageism and age discrimination in societies leads to approaches that prioritize protection/safety over autonomy/independence and consider limitations as necessary. Older people are presumed as unable to decide, they are rarely consulted or their wills and preferences are devalued and ignored.
- Lack of informed consent about care, support and medical treatment
- Age-based restrictions including, inter alia, mandatory retirement ages, age limits in access to disability benefits, to credit and insurance, to health prevention and rehabilitation treatment and in training<sup>5</sup>.
- Restrictive practices, including denial of legal capacity, guardianship, rudimentary or abusive care practices (i.e. restraining, abusive prescription of drugs, etc)
- Systems of support for older people are underdeveloped and under-resourced and have been severely hit by budget cuts. Support is often targeted at covering medical and personal

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<sup>3</sup> See annex for legal provisions

<sup>4</sup> See Report of UN Special Rapporteur on the Rights of Persons with Disabilities regarding a human rights based approach to support

<sup>5</sup> Several studies and data are cited in this paper: [http://www.age-platform.eu/sites/default/files/AGE\\_IntergenerationalSolidarity\\_Position\\_on\\_Structural\\_Ageism2016.pdf](http://www.age-platform.eu/sites/default/files/AGE_IntergenerationalSolidarity_Position_on_Structural_Ageism2016.pdf)

care needs (ex. bathing, eating) failing to ensure their full participation in community (ex. to leave house, participate in training, interact with others, etc)

- Lack of supported decision-making systems. Some EU countries do not allow advance directives and lasting powers of attorney<sup>6</sup>.
- Lack of accessible, age-friendly environments and services, including adapted housing, public transport, clean public toilets, seating areas, digital services, etc
- Poverty and lack of adequate income: due to cuts in pensions and services older people have to pay more out of their pocket for their increased health and support needs
- Loss of networks of support and social isolation
- Housing shortages, rising rents, and gentrification in cities
- Lack of information about systems of support and opportunities for social and civic participation

There are some studies about ageism and age-based restrictions, social exclusion, long-term unemployment, social care deficits, human rights violations in care settings, but these are scarce, incomplete, do not allow easy comparison among countries and do not necessarily reflect the extent to which older people are denied autonomy and independence compared with other groups. There is very limited information regarding restrictions to legal capacity on the basis of age and EU projects have only focused on disability.<sup>7</sup>

#### Question 4

Despite its commitment to promote older people's independence (article 25 EU Charter), to date, the EU has not adopted any specific policy action targeting older persons rights, unlike other vulnerable groups, such as women, people with disabilities, children, LGBTI, etc. The implementation of the Council of Europe recommendation is largely insufficient<sup>8</sup>. Evidence from the national level illustrates that recent reforms have diminished access to support and caused financial hardship among older people<sup>9</sup>, creating a vicious circle of exclusion, poverty and dependency for many older people across the EU. Age-based restrictions in access to disability support have not been in the radar of the Committee on the Rights of Persons with Disabilities and states have largely failed to report on the situation of people who acquire disabilities in older age. Despite a general trend towards deinstitutionalisation, community based support remains largely insufficient.

#### Question 5

In most countries older people can file complaints either of an administrative nature (i.e. within a residential setting) or contact the national ombudsperson. However, there is overall under-reporting of cases of denial of autonomy and independence because of lack of knowledge or rights and absence of support. Legal proceedings are burdensome, costly and lengthy and most older people prefer not to go to court. Independent advocacy services<sup>10</sup> and better monitoring are necessary. Also

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<sup>6</sup><http://www.the-vulnerable.eu/>

<sup>7</sup><http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems>

<sup>8</sup><http://www.age-platform.eu/policy-work/news/efforts-implement-coe-recommendation-older-people-rights-are-insufficient-assesses>

<sup>9</sup> See for example the Netherlands where long-term care insurance has been abolished.

<sup>10</sup> See for example in Ireland SAGE: <http://sageadvocacy.ie/>

laws need to be reformed to address age discrimination, denial of legal capacity and strengthen support for the exercise of autonomy and independence.

### **Question 6**

States should have a legal obligation to prevent, address and provide redress for the denial of autonomy and independence by non-state actors.

## Annex – Relevant provisions at European level

### At EU level

Article 25 of the European Union (EU) Charter of Fundamental Rights recognises “the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”. Furthermore, the EU and all 28 Member States have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), which sets out the equal right of all persons with disabilities to live independently in the community (article 19) and recognizes their equality before the law (article 12). The CRPD however only covers older people with disabilities and has not been equally applied to people who acquire disabilities beyond certain age. Many national systems continue to foresee age limits in disability provisions and the EU has not questioned this in law or policy frameworks.

### At Council of Europe level

The European Convention on Human Rights enshrines in article 8 everyone’s right to respect for their private and family life, which cannot be violated except for reasons of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others. The Revised European Social Charter (RESC) includes a specific provision on elderly persons’ right to social protection (article 23) but this defines older people’s independence in a narrower way than for people with disabilities (article 15). Whereas the RESC calls on states to undertake measures and support people with disabilities to enable their *full* participation in society, including in education, employment and access to all services available to the public, article 23 only creates an obligation on member states to take action to promote older people’s participation “for as long as possible” by securing adequate resources and providing information. Moreover the elderly provision focuses on access to health and housing and allows the institutionalisation of older people. Therefore, it is obvious that there is a much narrower scope for older people’s autonomy and independence and fewer legal obligations for member states. The two provisions are provided below for the sake of comparison. The Council of Europe CM(2014)2 recommendation on the rights of older people recognizes older people’s autonomy and independence and calls on member states to support older people to fully participate in society. However, it also foresees restrictions and necessary safeguards to prevent abuse and also allows the institutionalisation of older people. Some of the most relevant provisions are provided below

### Text of Revised European Social Charter

Article 15 –The right of persons with disabilities to independence, social integration and participation in the life of the community

With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

to take the necessary measures to provide persons with disabilities with **guidance, education and vocational training in the framework of general schemes** wherever possible or, where this is not possible, through specialised bodies, public or private;

to promote their access to **employment** through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment

according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;  
to promote their **full** social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling **access to transport, housing, cultural activities and leisure**.

#### Article 23 – The right of elderly persons to social protection

With a view to ensuring the effective exercise of the right of elderly persons to social protection, the Parties undertake to adopt or encourage, either directly or in co-operation with public or private organisations, appropriate measures designed in particular:

- to enable elderly persons to remain full members of society **for as long as possible**, by means of:
  - adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life;
  - provision of information about services and facilities available for elderly persons and their opportunities to make use of them;
- to enable elderly persons to choose their life-style freely and to lead independent lives in their familiar surroundings **for as long as they wish and are able**, by means of:
  - provision of **housing** suited to their needs and their state of health or of adequate support for adapting their housing;
  - the **health** care and the services necessitated by their state;
- to guarantee elderly persons **living in institutions** appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

#### Relevant provisions of CM(2014)2 Recommendation

9. Older persons have the right to respect for their inherent dignity. They are entitled to lead their lives independently, in a self-determined and autonomous manner. This encompasses, inter alia, the taking of independent decisions with regard to all issues which concern them, including those regarding their property, income, finances, place of residence, health, medical treatment or care, as well as funeral arrangements. Any limitations should be proportionate to the specific situation, and provided with appropriate and effective safeguards to prevent abuse and discrimination.