



5th February 2019

Questions on the normative framework of autonomy and independence

AGE Platform Europe's input

This short answer is submitted in reply to the call of the Chair of the Open-Ended Working Group on Ageing (OEWG). 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 countries¹ and 6 European organisations/federations² sit as well as reflections shared during an expert seminar on the human rights of older persons co-organised by AGE in 2018, webinars organised with AGE members and desk research using sources referenced in this document.

Separate answers covering normative elements on long-term and palliative care, as well as questions on social protection and social security, and education, lifelong learning, training and capacity building, are also submitted.

Further resources:

- [AGE Platform Europe's submission on questions on autonomy and independence, 9th session of the Open-Ended Working Group on Ageing, 2018](#)
- [Older persons' self-advocacy handbook](#)

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¹ All EU countries with the exception of Croatia, Latvia, Luxembourg and Slovakia

² FIAPA, ESU, NOPO, EURAG, EDE, OWN Europe



Question 1: What are the legal provisions in your country that recognizes the right to autonomy and independence? Do they have a constitutional, legislative or executive foundation?

- In the European region, only the Council of Europe CM(2014)2 recommendation recognizes explicitly to 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.

Question 2: What are the key normative elements of the rights to autonomy and independence? Please provide references to existing laws and standards where applicable.

[See detailed normative elements \(affirmation of the right, scope, and state obligations\) in ANNEX](#)

- A right to autonomy, independence, choice, control and legal capacity should aim to ensure the full, effective and meaningful participation of older persons in social, cultural, economic, public and political life and educational and training activities.
- It should apply without discrimination or limitations of any kind, across all settings.
- This right involves several state obligations (see ANNEX).

Question 3: How should *autonomy* and *independence* be legally defined?

- Autonomy is the ability to live according to one's wills and preferences on an equal basis with others. It includes the ability to make one's own choices and decisions in all aspects of life and to have them respected. It also includes the ability to maintain their legal capacity to exercise those choices and decisions³.
- Independence is the ability to keep the control over one's life, and to exercise one's own choices and decisions in all spheres of life. Independence means that the older person is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities⁴, nor from the ability to remain fully integrated in society and in community life.

Question 4: What are the policies and programmes adopted by your country to guarantee older person's enjoyment of their right to autonomy and independence? & Question 6: Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to autonomy and independence, paying special attention to groups in vulnerable situation?

- There is little action across the European region in terms of guaranteeing older persons' right to autonomy and independence. Despite its commitment to promote older people's independence⁵ to date, the EU has not adopted any specific policy action targeting older persons' rights.

³ See definition of autonomy in the Annual Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, 13 August 2015, page 9; on legal capacity, see also the General Comment No. 1 (2014) on article 12 (Equal recognition before the law) of the Convention on the Rights of Persons with Disabilities.

⁴ See definition of independent living in the General Comment No. 5 (2017) on living independently and being included in the community of the Committee of the Rights of Persons with Disabilities, page 4.

⁵ Article 25 of the European Union 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".

- Initiatives have been taken for other discriminated groups, such as women, people with disabilities, children, LGBTI individuals, etc. However, the intersectionality between those grounds and age has not been explored.
- European Union's Structural and Investment Funds (ESIF) include a condition on social inclusion and the obligation for states accessing those funds to develop strategies on the transition towards community-based care and support services. This has triggered a number of policy and legislative reforms across European Union states⁶. However, community-based services remain scarce and older people are little involved in such reforms.

Question 5: What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

- Challenges include the lack of consistent understanding and standards around older people's autonomy and independence in the European region 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. The understanding of autonomy and independence in old age is often limited to situations of ill-health and impairment.
- 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 disability⁷.
- Other challenges include, inter alia, the prevalence of substitute decision-making and guardianship practices; cuts in and lack of access to community services, which hinder the ability of older people to remain independent and integrated in the community⁸; 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 training⁹.

Question 7: The design and implementation of normative and political framework related to autonomy and independence included an effective and meaningful participation of older persons?

There are mechanisms for the participation of older people in consultations, which are sometimes compulsory; however, such participation is unequal in terms of meaningfulness and real impact. Moreover, given the little action undertaken around the autonomy and independence of older persons, opportunities for participation are extremely scarce.

⁶ Such condition is based on article 19 of the Convention on the Rights of Persons with Disabilities, which the EU has ratified. For an overview of the implementation of transition strategies triggered by the condition mentioned: <https://communitylivingforeurope.org/>

⁷ On the intersection between age and disability, and on the specific challenges facing older persons with disabilities, see the report of the Expert Group Meeting on Supporting Autonomy and Independency of Older Persons with Disabilities, 2017: https://www.ohchr.org/Documents/Issues/Disability/SupportingTheAutonomy/SummaryNote_EGM_OPWD.docx

⁸ In the Netherlands, for instance, there is a tendency to restrict local transport only to those services that are profitable. Consequently, older people living in the countryside, in smaller villages but also in some urban areas do no longer have accessible public transport, which causes isolation. A decrease in the number of post offices and mail boxes, and similarly a closure of bank offices and cash machines, are also detected.

⁹ Several studies and data are cited in this paper: http://www.age-platform.eu/sites/default/files/AGE_IntergenerationalSolidarity_Position_on_Structural_Ageism2016.pdf

Question 8: What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to autonomy and independence?

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 services¹⁰ and better monitoring are necessary. Also laws need to be reformed to address age discrimination, denial of legal capacity and strengthen support for the exercise of autonomy and independence.

ANNEX – Normative elements of the right to autonomy and independence

- **Affirmation of the right:**

Older persons have the right to lead independent and autonomous lives in line with their wills and preferences on an equal basis with others, without discrimination of any kind.

This includes the right to support to full participation in society, to make independent choices and have them respected, and to keep control over all aspects of life. This also includes the right of older persons to equal legal capacity.

- **Scope:**

The right to autonomy, independence, choice, control and legal capacity covers all aspects of life.

- **State obligations:**

States Parties shall have a duty to take all appropriate measures:

- To support older persons to exercise the right to legal capacity, autonomy and independence and to make choices.
- To ensure equal opportunities to live and participate in the community, prevent isolation and segregation; this includes ensuring access to services in the community.
- To make support available on an equal basis across all living arrangements – at home, in the community and in residential settings – to ensure older persons' enjoyment of their right to choose where and with whom they live; guaranteeing the right to choose involves making alternatives available.
- To ensure the access to supported decision-making¹¹; this includes, inter alia, access to trusted support persons, peer support, advocacy (including self-advocacy support), assistance with communication and ensuring the accessibility of goods and services¹²; this obligation includes providing training for persons involved in the provision of supported decision-making.
- To ensure the ability of older persons to provide advance directives through which they can express their will and preferences with free, informed, genuine and irrevocable consent.
- To guarantee the enforcement of appropriate and effective safeguards to prevent abuse.
- To ensure effective access to justice and redress in situations of violation of the right to autonomy, independence, choice, control and legal capacity.

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

¹¹ On legal capacity and supported decision-making, see the report of the Special Rapporteur on the rights of persons with disabilities, 2018: <https://www.ohchr.org/Documents/Issues/Disability/A.HRC.37.56.docx>

¹² See General Comment No. 1 (2014) on article 12 (Equal recognition before the law) of the Convention on the Rights of Persons with Disabilities.