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AGE Platform Europe Position on Article 19 of the UNCRPD

"From the perspective of older people the right to independent living means an opportunity to choose whether they want to live in their own homes or in residential settlements. It also represents the existence of an adequate network of social services in their neighbourhood where they can ask and find the necessary support and social assistance, especially if they want to stay in their homes as long as possible. Independent living also means an opportunity to actively participate in social events in their environment and become an equal partner in the community life".

Zivot 90, Czech Republic, AGE Platform Europe member

In this paper AGE Platform Europe (AGE), the European network that represents directly over 40 million older people in the EU28, presents its views on how independent living for *older people with disabilities*[1], (i.e. adults who are faced with impairments and functional limitations for the first time when they reach old age) can be accomplished. Having gathered information from our members, we explain the challenges faced by this group in enjoying their rights under Article 19 of the UNCRPD. We refer to cross-cutting issues, such as equality and awareness-raising and provide recommendations on what the Committee could do to better integrate the intersection of old age and disability in its work. We argue that the Committee should address all forms of forced living arrangements and lack of autonomy, including in the community. We showcase that the existing human rights standards have not paid attention to the age-related barriers faced by older persons with functional limitations in equally accessing support services and discuss some of the key general services that should be accessible to older people with disabilities.

How to apply article 19 in the context of old age

While not all older people are persons with disabilities, the likelihood of acquiring a disability increases with age. In the EU people at the age of 65 are expected to live more than half of their remaining years with a frailty or disability[2]. They find themselves often socially isolated and are vulnerable to institutionalisation and structural abuse[3]. They are rarely aware of their rights and how they can get support to claim them, especially when they depend on others for assistance in everyday living. In 2015, the UN Independent Expert on the Enjoyment of All Human Rights by Older Persons published a report on care and autonomy that in addition to providing useful policy guidance reveals that substantive issues relating to independent living are often labelled or understood differently from the perspective of older persons[4]. Consequently, AGE brings related policy frameworks under the scrutiny of Article 19 of the UNCRPD in view of improving awareness of the specific situation of older people with disabilities. Our position builds on two key reference documents that were developed by older persons and other stakeholders, namely the *European Charter of the rights and responsibilities of older people in need of long-term care and assistance* and the *EU quality framework for long-term care services,*[5] as well as ad hoc consultation of our members.

[1] The Council of Europe makes a distinction between older persons and ageing persons with disabilities, i.e. individuals who age with a disability they acquired at a younger age. See here.
[2] European Commission (2013) *Staff Working document on long-term care,* based on data from 2009 for EU27
[3] Office of the United Nations High Commissioner for Human Rights, Regional Office for Europe (2012) *Getting a life: Living Independently and Being Included in the Community, A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities*, p.14; United Nations High Commissioner for Human Rights on the human rights situation of older persons (E/2012/51) submitted to the Economic and Social Council; Human Rights Committee (2004) Concluding Observations, Germany, CCPR/CO/80/DEU, para 17; AGE Platform Europe (2015) *Dignity and Wellbeing of Older People in Need of Care*
[4] For example, the concepts of 'care', 'long-term care', 'age-friendliness' and 'dependency' are widespread in the ageing sector.
[5] For further information see: www.wedo-partnership.eu

AGE work is supported by grants of the European Union and from fees contributed by its membership. The contents of this document are the sole responsibility of AGE Platform Europe and can in no way be taken to reflect the views of the European Commission.

Article 19 introductory clause

"In Ireland once you reach 65, you are not regarded as disabled, but old"

Age & Opportunity, Ireland, AGE Platform Europe

Older people with functional limitations do not always have equal choices to live in the community. Sometimes it is the law that establishes different definitions of disability and old age[6]: 'older' and 'disabled' persons can be subject to different administrations, budgets and eligibility criteria that determine the allocation of in kind and cash benefits[7]. Such age categorisations perceive disability in old age as a predictable or even inevitable situation and sustain the vision of older people as being less deserving of support to live independently or remain included in the community. They also impede older persons from identifying themselves as people with disabilities and therefore seeking protection under the UNCRPD.

Even where age barriers are extinct, strict definitions of disability or assessment based on the type of impairment or degree of incapacity may leave older people who do not suffer from specific or single pathologies, and those with complex high-support needs, completely or partially uncovered[8]. For example, our members report cases where support is medicalised; or conversely, only focuses on cleaning and grooming, excluding assistance aimed towards improving health and quality of life or preventing further disabilities. In addition, frailty, chronic illness and mental decline can accumulate and gradually aggravate in later life affecting multiple functions of the individual[9] - a process not always reflected in disability scales or national policies. Moreover, ageist attitudes lead to lower quality or fewer options of services, different levels of support, lack of preventive measures and abusive practices, such as delayed, refused, inadequate or undignified treatment[10]. Long waiting lists are also common problems when there is no statutory right to support for older people with functional limitations[11]. Despite this, only limited attention was given to the barriers faced by this group in State reporting and Committee conclusions. This is why AGE urges the Committee to address equality across the life course and determine whether such distinctions can be justified as reasonable and objective, or qualify as discrimination on the basis of old age and disability.

In addition, organisations of older people represent people with varying abilities and do not necessarily identify themselves as Disabled People's Organisations (DPOs). Subsequently, they are rarely consulted by national governments in the development and implementation of disability policies. A survey among AGE members revealed that across the EU there are still organisations of and for older persons who are not aware of the relevance of the UNCRPD for older persons, while the majority has not been involved in monitoring or implementation of the UNCRPD in their country. A small number is not even aware of the existence of the Convention. Member States need to be encouraged to include older people's organisations in consultations and national monitoring mechanisms, as well as to address older people in their reports and to raise awareness of the UNCRPD among the older population.

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[6] In France there are different schemes depending on whether the disability occurred before or after 60 years (MISSOC).

[7] In Hungary there are separate services for the elderly and people with disabilities (MISSOC)

[8] In Greece invalidity levels are calculated on account of certain illnesses (MISSOC). The Irish Disability Act defines disability as a substantial restriction, which results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes.

[9] The Independent Expert states that *'Older persons have different patterns of disease presentation than younger adults, they respond to treatments and therapies in different ways, and they frequently have complex social needs that are related to their chronic medical conditions.'* (paragraph 85)

[10] See WHO (2011) *European report on preventing elder maltreatment*, Equality and Human Rights Commission (2011) *Close to home-An inquiry into older people and human rights in home care*

[11] ENNHRI (2015) *Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care*

Article 19 (a) Choice

AGE members argue that in order to reflect the reality of older people with functional limitations, the application of this provision should reflect the view of the OHCHR that institutionalisation is *not 'just about living in a particular setting; it is, above all, about losing control as a result of the imposition of a certain living arrangement'*[12]. The Committee should give equal attention to human rights violations in institutions as well as those occurring in the community, with the aim of ensuring that older people with functional limitations are not forced into a particular arrangement or place of living.

The majority of older people wish to continue living at home. However, where community supports are limited or homes are not adapted to individual needs, there is no option but for older people to enter residential care or depend on their family. Home care is not always a statutory entitlement and older people do not have an automatic right to choose a care setting.[13] This leads to inadequate resources and barriers to living in the community.

Some older people (for example those without close family or social network) wish to have the option to reside in a care home where they can avoid the isolation, loneliness and feeling of unsafety of living alone, while continuing to live autonomously. Such arrangements represent for them 'living spaces' where they can socialise with peers, access leisure and personal development activities as well as adequate services by trained professionals - such as tailored support for people with dementia. Adapted living places can empower older people with functional limitations manage their own household and decide how to live their day to day life. The Independent Expert highlights that living in residential settings can be an autonomous decision of the individual that should be respected[14]. In addition, nursing homes may deliver some 'community support services' for older people living in the surroundings[15]. The process of 'deinstitutionalisation' should not deprive older persons of these options, as long as user control and high quality of services are enabled without limiting liberty, privacy, independence or leading to segregation.

> "*It took me three years as a child to learn not to wet my bed at night and now they want me to do it again because they don't have time to come and help me to the toilet at night!"*
>
> Testimony gathered in the frame of the EU project EUSTACEA

Isolation, lack of control of day-to-day decisions, disrespect for individual preferences, deprivation of liberty, breaches of privacy, etc. are not issues confined only to institutions. Older people who live in their own homes and receive assistance by professional or informal carers 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. A number of reports highlight the prevalence of elder abuse, which constitutes a form of 'institutionalisation' while living in the community, a risk exacerbated by unqualified caregivers, lack of support to family caregivers, absence of regular monitoring, lack of application of adequate quality standards, focus on profit-making, limited staff and resources[16]. With little to no social protection for older people in need of support, informal care at home remains the norm in many EU countries, regardless of whether it complies with human rights

[12] OHCHR (2014) Thematic Study on the Right of Persons with Disabilities to live independently and be included in the community (paragraph 21)

[13] See Irish Equality Authority (2001) *Implementing Equality for Older People*, p. 50-51, Cahill, O'Shea and Pierce (2012) *Creating excellence in dementia care: a research review of Ireland's national dementia strategy* and ENNHRI (2015) ibid 11

[14] Paragraph 74

[15] For example, professionals from the care home doing visits to the home of the older persons, or older persons living in their homes but having access to temporary day or night care in the facility. The Independent Expert also argues that *'Flexible and open care institutions have been established in several countries in order to avoid such institutionalization, with free provision of medical home care, including administration of medication and infusions. Such services have improved the quality of life of older persons by enabling them to stay at home'*. (paragraph 75)

[16] See WHO (2011) ibid 10 and UN DESA (2013) *Neglect, Abuse and Violence against Older Women*

obligations and personal preferences[17]. This explains why older people advocate moving from a traditional, paternalistic and rigid form of care to more flexible and person-centred support that reflects the wide diversity of needs and expectations, rather than eliminating a certain type of living arrangement. Moreover, we witness lately a trend to force older people to informal care because families can no longer afford to cover the expenses of professional care. This exposes them to risks such as inadequate care, abuse and limited autonomy as it is done without prior assessment or adequate support. In addition, sometimes older persons with very complex medical and dependency needs, find themselves with practically no choice, as available services are either not tailored to their situation or necessary adaptations and level of support are not affordable. For example in Ireland, such cases end up in acute hospital departments. The availability and quality of services also vary between and within countries, as it is often the local and regional authority that is responsible for care. States should ensure that people with disabilities are not penalised or forced to move to another place because of a lack of support in their own community. In addition, they should offer accessible and sufficient information on available options and support for decision-making.

Article 19 (b) Support

AGE Platform Europe, with a large European partnership in the frame of the EU project WeDO, developed the following comprehensive definition of services that should be available to older persons with functional limitations: *"They need to encompass prevention, rehabilitation and enablement, cure and care, including end-of-life care. They combine health and social care for activities of daily living (ADL) such as eating, bathing, dressing, grooming, housekeeping, and leisure. They also cover the 'instrumental activities of daily living (IADL)' such as managing one's finances, shopping, using the telephone, transportation, and in some countries other activities such as taking medication. They can be delivered in various settings spanning the continuum from the beneficiary's home to intermediate care and (semi-) residential facilities."*

Across the EU we come across laws and policies that distinguish between people with disabilities of working age and those that are eligible for old age pension. In France, people over the age of 60 are not entitled to a disability allowance but fall under a different scheme, which provides less generous means-tested care packages that – unlike the disability benefit - cannot be used to remunerate the spouse, cohabitant or legal partner of the individual.[18]. In Romania and Ireland, no regular review of needs is available for older persons[19]. At least 8 EU countries do not offer personal assistance in old age[20]. In several countries there exist specialised residential facilities, such as nursing homes or senior homes, targeting only older persons. At the same time advocacy services for older people are lacking. While the Committee has expressed concern about linking the eligibility of social services and personal assistance to specific impairments or grades of disability, it has not stated whether age-based differential treatment and services constitutes discrimination.

According to the EC/SPC report on social protection for long-term care, *'just two hours care every day can cost more than many people's pension, while institutional care could cost a multiple of the average pension'*[21]. Yet to date, older people do not receive financial support complementing their contributory pensions. According to the UN Special Rapporteur on disability, this poses a threat to older persons' income

[17] Social Protection Committee and European Commission (2014) *Adequate Social Protection for long-term care needs in an ageing society*

[18] The age barrier in the French system should have been removed by the 1st January 2011, but it has been retained in the recent Law on the adaptation of society to ageing. See analysis by French Alzheimer society and FNAPAEF

[19] For Ireland this is the case for those in nursing care

[20] See, ENIL report on personal assistance. According to MISSOC, for Slovakia the threshold is set at 65 whereas in Finland "*Personal assistant by the Services and Assistance for the Disabled Act is meant for persons whose need of assistance is not mainly caused by illnesses or injuries that have begun, increased or worsened with high age or due to degeneration related to high age".*

[21] Social Protection Committee and European Commission (2014) ibid 17

security and their right to live independently[22]. The Council of Europe Recommendation on the Promotion of the Human Rights of Older Persons states that care should be affordable and programmes should be in place to assist older persons with covering the costs. The ageing population puts pressure on public budgets to provide services for older people and this has created a trend to individualise the risk of long-term care, asking older persons to buy services in the private market or rely on informal care. AGE agrees with the Independent Expert on the rights of older persons, who has underlined state obligations to provide adequate support to family carers and asks the Committee to ensure that services are accessible without impoverishing the individual or their family, nor endangering the rights of the caregiver and the person in need of support.

Support services should also include a right to the adaptation of the living environment. States should have an obligation to provide financial aid for adjustments to housing as well as mobility aids and assistive devices, without which living in the community is impossible. They should also ensure that age limits in access to credits do not impede older persons with disabilities from accessing loans necessary to make such adaptations. Last, support should not exclude end-of-life situations and palliative care, which are not adequately covered by the human rights framework[23].

Article 19 (c) Access to mainstream services

For AGE, the implementation of this provision should take due account of the WHO Framework for Age-Friendly Environments[24], which provides policy guidelines aiming to create inclusive societies by removing age-related barriers, ensuring equal access to general services and involving older persons in the design, implementation and monitoring of policies. Accessibility, affordability, reasonable accommodation, information and support are necessary elements for the realisation of this right. The Independent Expert has also highlighted the *'need to foster age-sensitive communities and age-friendly environments to help older persons retain their autonomy and be active, and be integrated effectively in all aspects of life'.* This means ensuring equal access to wide range of services of high quality also in remote/rural areas. This right also calls for equal opportunities to participate to social networks, associations and events, which should be accessible and affordable.

Recommendations

The CRPD Committee should:

- Recognise the systemic, multifaceted, structural discrimination faced by older people with functional limitations in the context of the right to independent living;
- Raise awareness of the relevance of the UNCRPD among older people's advocates, with a view to increasing their participation in monitoring its implementation;
- Ensure an equal application of disability rights across the life course, fighting ageist stereotypes and constructing disability in a manner that does not justify the exclusion of older people;
- Encourage States to systematically report on the barriers faced by older people with disabilities;
- Provide legal clarity and policy guidance for duty bearers, human rights practitioners and self-advocates on the specific human rights challenges in the intersection of old age and disability, including through a General Comment on the rights of older persons with disabilities.

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[22] Special Rapporteur on the rights of persons with disabilities (2015) A/70/297
[23] UN Secretary General (2011) *Follow-up to the Second World Assembly on Ageing* (A/66/173)
[24] http://www.who.int/ageing/age-friendly-world/en/