



30<sup>th</sup> June 2017

## **Draft General Comment on Article 19 (Living independently and being included in the community)**

### **Submission by AGE Platform Europe**

AGE Platform Europe, as the largest EU network of organisations of older persons, welcomes the draft General Comment (GC) on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which is a key element in the realisation of the rights of older with disabilities. In this submission we bring forward the views of the organisations involved in our network, which represent directly more than 40 million older persons living the European Union.

### **Setting the scene: the barriers to independent and community living for disability in 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<sup>1</sup>. Many of these older people require support in their everyday living, but in practice there are several barriers in accessing the support they need.

In several EU countries there is little to no right to social protection covering the care needs of older people<sup>2</sup>. Due to gaps in coverage, older people often have to pay out of their pocket for part or all of needs for long-term assistance. Many countries offer only means-tested support, which in some cases require older people to sell all assets, including their own homes, before public systems intervene<sup>3</sup>. Moreover, home care is not a statutory right for older people in all EU countries, which means that they may have access to less support if they decide to remain in their own homes. In addition, in most EU countries there exist age limits in access to disability benefits, mobility allowance and personal assistance, which put older people in need of support in a disadvantaged position compared to younger persons with disabilities<sup>4</sup>.

Today the vast majority of older people receive care at home from informal caregivers; this can be a legitimate choice, but it is often the result of a lack of sufficient and appropriate home care services, including limits to the number of hours of professional assistance older persons can receive per week. Moreover, informal caregivers receive little or no support in the form of respite care, training or psychological assistance. Such lack of support for informal caregivers combined with the limited support for older persons offered in the community result in higher risk of elder abuse, which most

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<sup>1</sup> European Commission (2013) *Staff Working document on long-term care*, based on data from 2009 for EU27

<sup>2</sup> Social Protection Committee and European Commission (2014) *Adequate social protection for long-term care needs in an ageing society*

<sup>3</sup> As highlighted in [a joint European Commission-OECD study](#) on social protection for long-term care, there is some level of means-test in public support in most countries. Whereas most of them apply limited means-test, some such as the US or England require older persons to use all their income – except from an amount for subsistence – and withdraw any support for those who have assets that they can use to pay for the care they need.

<sup>4</sup> For examples of age limits see [AGE response to OHCHR consultation on article 5 of the UNCRPD](#)



often take place at home by family members or carers<sup>5</sup>. For example, a report by the UK Equality and Human Rights Commission has highlighted many instances of neglect of older people, visits of carers as short as 10 minutes, abusive practices and overall undignified treatment of older people receiving care at home<sup>6</sup>.

One of the trends induced by the recent crisis is that older people are taken out of residential care because it is costly and are forced into home care, without any assessment of their care needs nor sufficient support. This increases the risk of unmet needs, elder abuse, isolation and declining health. Under similar considerations, the [Council of Europe Commissioner for Human Rights](#) stated in a report on the impact of austerity in 2012 that *“many families are reportedly withdrawing older persons from residential care centres and taking them home in order to benefit from additional income in the form of their pensions. While de-institutionalisation is a welcome process, if carried out as part of comprehensive policies and with additional support for the elderly persons and families concerned, it may result in higher levels of abuse, including violence and neglect, when it takes place without sufficient control and adequate support from the state.”*

According to European data (and based on the views of AGE members) the vast majority of older people wish to be cared for at home. However, because of ageist attitudes older persons are often considered as a “burden” and –as result – some feel incapable or non-deserving of help to stay at home. Combined with the aforementioned underdevelopment of adequate, quality support at home, this constitutes a barrier to the exercise of a genuine freedom of choice of the place of residence by older persons with care needs, and explains why moving to residential care is often the only option older persons are left with.

However, there are still people who, in full use of their right to autonomy and self-determination, wish to live in a residential setting for various reasons, for instance because they are afraid, feel isolated or prefer not to live alone, because they do not have any family, because they might experience a greater feeling of safety, because they feel they can be better integrated in the community thanks to the activities and services organised in the residential setting than when at home as social and family networks in old age shrink, etc.

Several good practices of residential settings that offer quality, person-centred, affordable and appropriate support in the community are available across EU member states. For example, residential services built in the centre of urban areas, offering private apartments alongside tailored support services. Such settings are integrated in the community, where they sometimes offer services such as restaurants, libraries, hairdressers, etc. for everyone and not just for the older residents. They often promote intergenerational exchange by organising activities between older persons, local schools and sport clubs, and encourage the involvement of volunteers to help the older residents maintain their ties with the community. Living in such residential settings is a life choice and sometimes part of a life plan about how and where one wants to spend their old age. The choice of older people to live in a residential setting should thus be equally respected.

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[http://www.who.int/violence\\_injury\\_prevention/violence/elder\\_abuse/Elder\\_abuse\\_infographic\\_EN.pdf?ua=1](http://www.who.int/violence_injury_prevention/violence/elder_abuse/Elder_abuse_infographic_EN.pdf?ua=1)  
<sup>6</sup> Equality and Human Rights Commission (2011) [Close to home-An inquiry into older people and human rights in home care](#)

## AGE's recommendations

- **Need to preclude institutionalisation wherever it occurs**

Whereas **Paragraph 15c** clearly states that institutionalisation is not limited to a particular setting, in our view it does not adequately address the risk of institutionalisation and other human rights violations when people live in the community without adequate support or when care is so rudimentary or inadequate that it does not allow individuals to retain control over their daily choices and does not offer them opportunities to participate in the community. As explained above, elder abuse and isolation are important and common problems among older people living in the community and the concept of de-institutionalisation should equally address those cases, without creating fertile ground for such practices to continue in any care setting, i.e. at home, in community or residential settings.

## Proposals for amendments

The GC should preclude institutional culture no matter where it occurs and regardless of the size of the care structure. This would include also individual apartments where people with disabilities have no control over their lives. This is why we suggest eliminating in **Paragraph 15c** reference to sizes of establishments as follows:

*15 (c) Both concepts, i.e. independent and community living, refer to **life settings without institutional care characteristics, outside of institutions, including large or smaller group homes** Institutionalization is not about living in a particular setting, it is, first and foremost, about losing control as a result of the imposition of a certain living arrangement. Therefore, neither large scale institutions **structures with more than a hundred residents** nor smaller group homes **with five to eight individuals or any other services and living spaces** can be called independent living or community living arrangements, **as long as they do not allow for individual choice and control and they lead to isolation or segregation from the community.***

Although institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: **settings where people with disabilities are isolated from the broader community and/or compelled to live together against their will; they do not have sufficient control over their lives and over decisions which affect them; the requirements of the service provision tend to take precedence over their individualised needs.**<sup>7</sup> ~~isolation and segregation from community life, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control, however, these choices are limited to specific areas of life and do not change the segregating character of institutions~~

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<sup>7</sup> Based on a definition provided in European Commission (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, p. 9, available at: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes>

As explained above isolation does not only take place in institutions but also when older people live alone in their own homes without support to participate in the life of their community. This is why **paragraph 51** should reflect that isolation should be tackled wherever it occurs

*51. Support should always be based on the individual requirements, not the interest of the service provider. States parties should establish monitoring mechanisms of service providers, adopt measures which protect persons with disabilities from being hidden in the family or isolated ~~in institutions~~, protect children from being abandoned or institutionalized on the grounds of disability and establish appropriate mechanisms to detect situations of violence against persons with disabilities by third parties.*

- **Need to distinguish between residential and institutional care**

Article 19 does not impose a certain form of living arrangement, but enshrines a right for people with disabilities to choose where and with whom they live, the type of care and support they receive and who provides it. Interdependent with this right is the right to a continuum of quality, person-centred, affordable and appropriate health and other support and care services which are available and accessible in the residence of choice.

Older people may choose to live at home alone or with their family or choose a form of accommodation in which one lives with others, with shared facilities and social support and with nursing and/or other forms of health-related support, including palliative or end of life care. As long as this is the choice of the older person who retains the control over their everyday decisions and the services are community-based (i.e. see above mentioned examples of services that respect individual autonomy, do not lead to segregation and offer opportunities for participation in the community) such residential settings must not be equalized to institutional settings and they must be considered as an integral part of community-based services. A wide range of choices, including residential settings, must be available to ensure older people have a right to choose the type of care, provider and setting they prefer, without being penalised based on their choice. The right to choose one's living arrangements, including residential settings, is not at odds with the concept of de-institutionalization, as institutionalization does not refer to a 'particular setting' but to 'loss of control due to the imposition of a certain living arrangement' (Draft GC 5, paragraph 15c).

The draft GC does not make a clear distinction between residential and institutional care, but it appears to preclude any type of residential facility. For example, Paragraph 47 refers to 'the right to choose a residential, institutional setting'. Moreover, Paragraph 28 refers to 'residential services' as 'transitional services', while – as explained above – such services may be part of long-term living arrangements for older people. Such statements are in contradiction with Article 19(b), which refers to 'residential and other community support services' among the range of services to be put in place by the States, on the condition that they 'prevent isolation or segregation from the community.' Whereas services with institutional care characteristics must be precluded, other residential services must be retained as an integral part of support to independent and community living.

## Proposals for amendments

**Paragraph 28:** residential services may be necessary to ensure people with disabilities and older people can live independently in the community and not just as transitional services. This must be reflected in the GC as follows:

*28. ...Residential services are services which offer persons with disabilities support as well as a place to live. Such services form an integral part of community-based services, as long as they support independent living and prevent isolation or segregation from the community. They can be useful when persons with disabilities make the transition from institutional settings to independent and community living and might be necessary for persons who have lived in institutional settings for a long time and need to find out how and where they prefer to live.*

### Paragraph 35

Ensuring access to housing to persons with disabilities should not be presented as being in contradiction with ensuring access to residential care, for residential settings are a place of living that older persons may wish to choose freely. By mentioning places where “many people with disabilities have to live in the same building, complex...” as an illustration of the violation of article 19 the GC creates confusion regarding the right to choose a residential living arrangement. The paragraph should be rephrased as follows:

*35. In terms of material scope, article 19 covers access to housing, individual services and community facilities and services. Access to housing means having the option to live in the community just like persons without disabilities. Article 19 is not properly implemented if housing is only provided in specifically designed or isolated areas and if people with disabilities are only given the option arranged in a way that many people with disabilities have to live in the same building, complex or neighborhood inhabited only by persons with disabilities.*

### Paragraph 47

The GC should make a clear distinction between maintaining institutions and taking steps to ensure that people with disabilities and older persons have a choice to live in community-based residential settings, by ensuring the availability of such services.

*The right to decide where, how and with whom to reside also embraces the decision to live in institutional residential care settings, because there is no obligation to live under a particular living arrangement. However, as article 19 of the Convention is about being included in the community, the right to choose a residential setting, institutional setting does not correspond with a states' party duty to maintain institution or to ensure the availability of residential support services.] States have an obligation to ensure the availability of a wide range of community-based services, including residential services where people with disabilities can enjoy their right to live independently by exercising their autonomy and control over all their living arrangements, including choice of appropriate support, and enjoy their right to be included in the community.*

**Paragraphs 33, 48, 51, 64, 93, 94k:** to avoid confusion between residential and institutional services, the word to residential needs to be deleted in these paragraphs.

*33... Various de-institutionalization programs have shown that the closure of residential institutions, regardless of their size and the relocation of inhabitants in the community or*

*with their families, in itself is not enough. Unless such reforms are accompanied by comprehensive service and community development programs, including awareness programs, they largely fail.*

*48... Examples include guardianship and mental health laws which force persons with disabilities to live in institutions as well as laws on social protection or building law which prioritize ~~residential~~ or institutional services.*

*51. States parties should also prohibit that directors and/or managers of residential **services and** institutions become guardians of the residents.*

*64... Training should also be directed at professionals who formerly worked or currently work in ~~residential~~ institutions to ensure that they actively contribute to de-institutionalization and the transformation of support services*

*93. Investing money obtained in the framework of international cooperation into development of new ~~residential~~ **institutionalizing structures** is not acceptable as it leads to segregation and isolation of persons with disabilities.*

*94 (k) Put in place appropriate mechanisms to monitor existing institutions ~~and residential services~~, de-institutionalization policies and the implementation of independent and community living.*

- **Need to ensure efficient and rights-compliant transition mechanisms**

An adequate transition from institutional to community-based care is a process that requires resources and time in order to avoid creating care gaps and increasing the risk of isolation and neglect. A successful transition means allowing all persons with disabilities to access personalised support that respects their preferences and allows them to be integrated in the community and remain autonomous, regardless of their place of living. Such process requires investments in formal community services as well as through acknowledging and supporting the role of informal caregivers.

A strategy for de-institutionalization should be guided by a philosophy of transition and not radical closure of institutionalizing settings. This includes involving services that have been delivering institutionalizing care but show willingness to transform service delivery towards community person-centered type of support and to meet the conditions of article 19.

The GC in its current wording acknowledges the need for investments in community-based support as part of the process but does not state with enough clarity the ‘transitional’ character of any strategy for de-institutionalization nor the possibility to adapt, innovate and transform existing services.

Moreover, the transition to independent and community living should be based on viable and sustainable solutions that respect intergenerational fairness and do not exclude those with high support needs. Finally, the GC should avoid ageist language that creates barriers to intergenerational exchange, while at the same time promoting the right of all age groups to live with people of their age.

### **Proposals for amendments**

**Paragraph 53** refers to the role of family caregivers and highlights their role in ensuring independent living. While rightly stating that such role should not equal to a transfer of responsibility from the State towards families, this should not prevent the GC from referring to the need to support family caregivers, for the reasons explained above.

53. States parties should also ensure that autonomy and self-determination of persons with disabilities concerning their living arrangements prevail and are protected in family contexts. Families can contribute to the realization of the right to independent living. *However their role of family caregivers does not replace States parties obligations in the exercise of the right to living independently and being included in the community. States should therefore ensure that informal family caregivers receive adequate support in the form of training, support, psychological assistance, respite care and carer's leaves for those who have a professional activity, among others. States should also ensure that informal care is not imposed on families and remains a choice of both the informal carer and the care beneficiary through offering a range of adequate alternative care options in the community. State Parties should prevent and combat...*

**Paragraph 56** should reflect the need to make sure de-institutionalization adopts the form of a transition and not a radical closure of existing structures, without ensuring the availability of services in the community. It should also accept within such process the conversion of institutionalizing care structures under certain conditions into person-centred community-based residential care, provided that circumstances and characteristics are subject to change and do not perpetuate segregation or isolation (for instance due to remote location of establishment)

56. States parties should adopt a strategy for de-institutionalization. De-institutionalization includes the duty to implement structural reforms. It requires a systemic transformation which goes beyond the *progressive* closure of institutional settings *or their transformation into residential care that allows for community and independent living, whenever such transformation is possible and compliant with the requirements of article 19 (i.e. non segregation or isolation)*. It ~~and~~ requires the establishment of a range of individualized support services as well as inclusive community services *in order to ensure that the process does not lead to isolation and inadequate or no support in the community*. Therefore, a coordinated, cross-government approach which ensures reforms on all levels and sectors of government, including local authorities, is necessary. It is also important that resources are allocated to community support services and that the creation of new *institutionalizing care structures* ~~or the structural refurbishment of existing institutions~~ is ended. If support services do not exist, it is relevant for States parties not to reproduce outdated models or create *institutionalizing care structures*, but rather implement approaches which enable persons with disabilities to independent and community living.

The GC, whilst stating that de-institutionalisation is not enough to realise the rights to independent living, on several occasions, uses the term de-institutionalisation as synonym to independent and community living. Ex. **Paragraphs 57 and 85** instead of 'de-institutionalisation' should refer to 'independent and community living'.

**Paragraph 58** should reflect the differential treatment of older persons with disabilities based on their age by making reference to age criteria, as follows

58. ...A human rights-based approach to support also means that support systems, including personal assistance, do not exclude persons with disabilities because of their impairment, *age* or the kind of support they require....

**Paragraph 20** should address the ongoing trend of community services to exclude people with support needs. It should moreover reflect the growing number of older people with high support

needs and the need to offer solutions that take due regard of intergenerational fairness to avoid a disproportionate burden for younger generations.

*20. In some State parties, individuals with high demands in personal assistance are sent to institutions if the expected calculated costs for independent and community living exceed a predefined level/amount of institutional costs. Another situation identified by the Committee is the presumption that persons with high support requirements are unable to live independently and be included in the community. Particularly, persons with intellectual impairments, are often assessed as being unable to live outside of institutionalized settings. Such reasoning opposes article 19 of the Convention which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirement. Additionally there are long waiting lists and an increasing tendency among home and community care providers to cherry-pick and exclude individuals with high demands or challenging behavior, forcing them to remain at home with inadequate support or to be institutionalized in a hospital or psychiatric ward. This cherry-picking trend among community care providers increases the risk of abuse and violates the human rights of the most vulnerable. Finally in a context of demographic ageing and expected sharp increase in the numbers of very old persons with high support needs, the objective of independent living must be reconciled with intergenerational fairness notably by lowering the demand for support through the creation of age-friendly environments and ICT enabled support to independent living.*

**Paragraph 21** contains some problematic language, reflecting ageist assumptions and not allowing the development of intergenerational relations. The term elderly must be avoided as it is stigmatizing and reflects frailty and dependency.

*21. One's lifestyle, activities, preferences and social network evolve with age and it is important for ~~Different cultures can also challenge~~ the concept of Independent living to take on board that life-cycle evolution while promoting intergenerational living in the community. When young persons with disabilities are forced to live in institutional settings with older elderly persons they may face the risk of living in an environment where the culture of support and services may be determined by the age of the majority, hence not allowing young persons with disabilities to interact with people of the same age, become part of the local youth community ~~develop an identity~~ and live their life as any other ~~in an age-appropriate mode~~ as 'young persons living in their area.*

### For more information

- [AGE submission to consultation on article 19](#)
- [On quality long-term care and fight against elder abuse](#)
- [Older persons' self-advocacy handbook](#)
- [Toolkit on the dignity and wellbeing of older persons in need of care](#)

For more information you may contact [Nena Georgantzi](#), Human Rights Officer & [Borja Arrue Astrain](#), Policy and Project Officer responsible for long-term care and elder abuse