# Draft General Comment No. 5 on Article 19 of the UN Convention on the Rights of Persons with Disabilities

# Submission by the European Network on Independent Living

## About the submitting organisation

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL’s mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL is a founding member of the European Coalition for Community Living (ECCL) and the European Expert Group on the Transition from Institutional to Community-based Care. ENIL has Participatory Status with the Council of Europe, a Consultative Status with ECOSOC and is represented on the Advisory Panel to the EU Fundamental Rights Agency’s Fundamental Rights Platform.

## Introduction

ENIL welcomes the draft General Comment on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), as an important step in facilitating the implementation of disabled people’s[[1]](#footnote-1) right to independent living. Since the adoption of the CRPD in 2006, we have been raising awareness about the barriers to independent living and the lack of progress in implementing Article 19 in different reports, briefings, events and in our submission for the Day of general discussion on Article 19[[2]](#footnote-2). Our latest report ‘The Right to Live Independently and to be Included in the Community – Addressing Barriers to Independent Living across the Globe’[[3]](#footnote-3), the draft of which has been shared with the Committee on the Rights of Persons with Disabilities (CRPD Committee) in March 2017, identifies the following seven barriers to the realisation of independent living globally:

* Misunderstanding and misuse of key terms
* Negative attitudes and stigma
* Lack of support to the family
* Prevalence of institutional services
* Barriers related to community support services (which include the lack of funding, and the absence of national legislation guaranteeing the right of disabled people to community-based support)
* Barriers in mainstream services and facilities
* Barriers to other CRPD rights that impact on independent living

ENIL’s views, which have been set out in this submission, have been informed by the findings of this report and address the barriers faced by disabled people from around the world when it comes to independent living. In addition, we have prepared a shorter, joint submission with the European Disability Forum and Inclusion Europe, which focuses on five key areas which our organisations agree require attention by the CRPD Committee:

1. more clarity is needed on alternatives to institutional care;
2. family support is key to independent living;
3. more emphasis is needed on funding and data collection;
4. deinstitutionalisation strategies must be time-bound and adequately resourced;
5. there is a need to strengthen the focus on intersectional discrimination experienced by disabled people.

***The importance of the General Comment on Article 19***

The General Comment (GC) on Article 19 should provide clear guidance to States Parties on how to address the barriers disabled people face, to facilitate the closure of institutions for disabled people and the development of quality community-based services that support independent living. The General Comment should leave no room for different interpretations of obligations under Article 19 CRPD, resulting in disabled people being denied their human rights.

ENIL’s submission highlights parts of the draft GC that are highly problematic, provisions that should be strengthened and provisions that of particular importance, and therefore should remain in the GC.

## Provisions that do not support independent or community living

ENIL and its member organisations are extremely concerned that a human rights treaty should recognise the right of disabled people to live in segregating settings (see Paragraph 47 of the draft GC), exposed to human rights violations that occur there, and knowing that such segregation will consequently be financed and otherwise supported by Governments. The CRPD’s *raison d’être* is to end the segregation and social exclusion of disabled people, not to preserve status quo.

***Paragraph 47***

As stated above, we are seriously concerned about this paragraph, which suggests that some disabled people may choose to live in institutional care settings. Despite the second part of the paragraph, which notes that States do not have a duty to maintain institutions or to ensure availability of residential support, this paragraph gives States a green light to continue maintaining institutional care settings and institutionalising disabled people.

There are a number of elements the CRPD Committee must consider, and these are set out below.

1. **Choice**

A choice can be respected, even protected, but the state should not financially provide for all the choices people make; this includes suicide, for example. Resources should be allocated only if they allow the disabled person to live in the community, in line with Article 19 CRPD.

It is true that, as long as institutions are open, there will be disabled people seen as requiring or wanting a place. Although some disabled people may be asking to stay in an institution, or to be placed in one, one must look at the reasons for this ‘choice’. Such reasons can include:

* Some people have lived in institutions their whole lives, therefore it is the only environment they know. Without preparation and peer support from those with a similar experience, who now live in the community, it is natural they may not want to leave the institution;
* People may be given no choice as to where they will be moved and with whom they will live; therefore, they may not want to leave their friends in the institution, or the carers they are familiar with;
* For many people, the choice to live in an institution is made by their guardian, or they may feel pressured into making such decision for different reasons (for example, because they do not want to be a burden to their family); in many cases, families lack support to be able to keep their child at home, or may be disabled or ill themselves;
* In many countries, there are no real alternatives to institutional care, or they may be inadequate or of poor quality - therefore, institution may been seen as a ‘safer’ option by the disabled person and/or those close to them; due to long waiting lists for community-based support in some countries, disabled people or their families may have no choice but to ‘ask’ for a place in an institution;
* If the closure of institutions is not accompanied by awareness raising activities and work with the communities, disabled people may suffer abuse and hate crime in their new homes in the community; they may, therefore, want to go back to the institution.

It is important to address all these reasons during the process of deinstitutionalisation, and ensure that people’s fears and concerns, and those of their families, are taken into account. During the deinstitutionalisation process in Sweden, while institutions were closed with a lot of opposition, in the end, nobody regretted moving into community. On the other hand, as long as countries are allowed to keep institutions open, there will be incentives for disabled people to be institutionalised and there will be fewer resources to develop community-based services.

1. **The difference between institutional care and residential support services**

While Article 19(b) refers to residential [and other community support] services, it is clear from the qualifiers – ‘necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’ – that these do not refer to institutional care services.

ENIL accepts that some disabled people may choose to live together with other disabled people, and if that is the case, they can do so on an equal basis as non-disabled people. However:

1. this should be their choice, and the principle of non-discrimination should apply. This means that there should be a range of genuine independent living options in the community, to allow for real choice. Adequate information and support, including from peers, should also be provided to assist with decision-making.
2. the place they live in should resemble a home. This requires that:
   * the number of people living together is not higher than is usual (depending on the average number of children per household, local culture etc.).
   * the provision of support and housing is separated, to allow for greater flexibility. Thus, if someone is unhappy about the services they receive, they might decide to change the service provider and continue to live in the same place or elsewhere, with or without the same people.
   * there is no block treatment – provision of services is personalised and depends on individual needs and preferences. Block treatment, where all people living in a certain place receive the same services, is one of the key characteristics of institutional culture.
   * people can make choices about their daily lives – for example, when to get up and go to bed, what to eat, whether to go out and when, whether to have friends over etc.
   * individual privacy is respected and people have personal space and belongings.
   * mainstream services and facilities in the area are accessible, so that disabled people are able to use the local transport options, go to work, see the local doctor, use the local hairdresser, access cultural and sports facilities, even if they need personalised support to do so.
3. **Conflict between Paragraph 47 and other provisions of the draft GC**

The inclusion in the draft GC of ‘institutional care settings’ among the range of services that may be provided by States contradicts many of the other provisions. For example, as stated in Paragraph 6, Article 19 is ‘a precondition for the implementation of the Convention across articles.’ Paragraph 16 adds that ‘institutionalised settings are not compliant with the concepts of independent and community living.’ Therefore, the draft GC recognises the possibility that some disabled people may choose to give up all of their rights by deciding to live in an institution – and accepts such a possibility.

In Paragraphs 25 – 26, the draft GC recognises that disabled people’s choices may be severely restricted or influenced for different reasons. Importantly, paragraph 65 states that ‘misallocation of resources into institutionalised support services is a clear violation of article 19’. If however, States are to provide institutional care as one of the options to disabled people, they have to invest resources into them. Such contradictions will make it impossible for the States to understand what is, and what is not in line with Article 19 CRPD.

## Provisions that must be changed, in order to support independent or community living

***Paragraph 14***

We suggest adding the following barriers: Failure to close long-stay residential institutions; Lack of accessible and affordable housing in the community; Lack of data; Continued investments into institutional care settings.

***Paragraph 15***

We suggest explaining the difference between residential support and institutional care. Although the paragraph explains what constitutes ‘institutionalised settings’, it does not explain what type of residential support services are referred to in Article 19(b). We suggest referring to some of the points we made above, under *‘The difference between institutional care and residential support services’.*

We suggest defining what ‘community-based services’ are. ENIL uses the following definition:

‘The development of community-based services requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, health care and other services and support, available and accessible to disabled people in mainstream settings. Disabled people must be able to access mainstream services and opportunities and live as equal citizens. Community-based services should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, the need for special transport because mainstream transport is inaccessible and so on. Group homes are not independent living and, if already provided, must exist alongside other genuine, adequately funded independent living options.’

***Paragraph 16***

We suggest adding that ‘home care’ services, where disabled people have no control over their support, cannot be considered personal assistance. In most cases, it is the different types of ‘home care’ services that are presented as personal assistance. We also suggest acknowledging that Article 19 reflects cultural diversity – States are required to develop a range of support services in the community, but this does not have to reflect a particular, ‘western’, model. States can decide what services to develop, provided that they respect the principles of choice and control by disabled people and non-segregation from the community.

***Paragraph 18***

With regard to ‘community living’, we suggest clarifying that this is not to be confused with communal living, nor does it refer to living in the same community as other disabled people. Rather, community living is about living included in the society.

***Paragraph 21***

We do not think young persons living in institutions with the elderly is a good example of cultural challenges. Any group of disabled people living in institutions – regardless of their age - is contrary to Article 19. Instead, we suggest explaining that independent living is often seen as a ‘western’ concept, promoting an individualistic and atomistic view of people. As such, it is thought to be incompatible with the communal cultures of some indigenous peoples and countries in Africa, Asia and the Pacific and Latin America, where mutual caring and support in the community is a norm and people continue to live with their families into adulthood.

Independent living, however, does not require leaving one’s family and community. For some people, it may mean moving away from their family, for others – it may mean living with their family. The key issue is that it must be the disabled person who makes the decision and this must be the person’s genuine choice; that is, the person’s choice is not restricted by environmental and attitudinal barriers and/or the lack of support.

***Paragraphs 24 – 26***

We suggest adding other ways disabled people’s choices may be restricted. This includes: long-term institutionalisation and the failure to prepare individuals for moving into the community, the lack of peer support, and long waiting lists for community-based support.

***Paragraph 28***

We suggest deleting the sentence ‘They can be useful…’ Instead, we suggest explaining the obligations of States to ensure that residential services do not retain institutional care characteristics, as set out in Paragraph 15. Any ‘residential services’ must ‘support living and inclusion in the community, and […] prevent isolation or segregation from the community’, if they are to be in line with Article 19(b). For this reason, States must separate the provision of housing from support, and should, among other, help disabled people find suitable housing, include social housing. Such services may also come under the heading ‘residential services’. (Please also see above, under *‘The difference between institutional care and residential support services’*).

***Paragraph 35***

We suggest adding that housing options, where people are obliged to use a day care centre or go to sheltered workshops, and do not have access to mainstream services, are also not in line with Article 19. This tends to be the case where residential settings (such as supported housing) for disabled people are built around a day care centre or a sheltered workshop, or where facilities such as a hairdresser, dentist, doctor and other are provided on site.

***Paragraph 38***

We suggest adding ‘sheltered workshops’ to the first sentence. In the sentence ‘Packages of indidivualised services, …’ we suggest changing ‘personal assistance’ to ‘home care’. This more accurately reflects the situation on the ground, where residential and home care services tend to be provided in serviced housing. It is important to understand that this is not the same as a disabled person living with a personal assistant in their own house, or a house they share with their family or friends.

***Paragraph 40***

We are concerned about the possible interpretation of the ‘minimum essential level of the right to live independently’, and suggest replacing it with ‘a standardised minimum support level sufficient to exercise the right to live independently in the community’. In order to save money, some countries are re-examining the level of support disabled people need, resulting in them receiving fewer and fewer hours of personal assistance support. Instead of going to the toilet, disabled people are expected to use diapers, for example, or to rely on their relatives for help. Therefore, the GC should make it clear that it is up to the disabled person to say what they consider to be the ‘essential level’ of support. This will depend on their impairment, but also their lifestyle, family situation, preferences etc.

***Paragraph 41***

We suggest this paragraph explains that the parts of Article 19 that are civil rights, and the parts that are considered social rights, do not work without each other. For example, a person cannot choose ‘where, how and with whom to live’ – the part that is immediately applicable – without having adequate support. If they do not have the support – the part that is subject to progressive realisation – their choice of living arrangements will be effectively taken away from them.

***Paragraph 42***

We suggest pointing out the importance of a timeframe, when it comes to ‘strategic planning’. Rather than States parties simply having the obligation to start planning, they should be required to put in place a reasonable timeframe for deinstitutionalisation, and should not delay the process unnecessarily or indefinitely.

***Paragraph 43***

Similarly to the point under Paragraph 40, we are concerned that suggesting States should implement ‘at the very least, minimum essential levels of each of the rights’ could be dangerous, leading to disabled people having some support, but not enough to live independently.

***Paragraph 44***

We suggest deleting the sentence ‘Retrogressive measures only should be adopted…’. Already, progressive realisation allows States to implement certain parts of the CRPD in their own time, depending on the resources they have available. Allowing them to also take retrogressive measures, in addition to failing to take positive measures, seriously jeopardises the implementation of the CRPD. It is also in contradiction with the human rights principles mentioned at the beginning of the draft GC, in Paragraphs 9 – 12, which point to the interconnectedness of human rights.

***Paragraph 51***

We suggest adding that monitoring mechanisms should involve disabled people as experts by experience.

***Paragraph 56***

We suggest adding that the closure of institutions must be a part of any deinstitutionalisation strategy, and that any deinstitutionalisation strategy must come with a reasonable timeframe, and with the necessary budget, in order not to delay the process of deinstitutionalisation unnecessarily or indefinitely.

***Paragraph 59***

When it comes to support assessment, having a family, a social network, income and so on should not been taken into consideration, only each person’s individual support needs.

***Paragraph 64***

We suggest adding that disabled people – as experts by experience - should be involved as trainers in any training on independent and community living aimed at different professionals.

***Paragraph 74***

We suggest adding the importance of services that facilitate the transition of young people into adulthood, including support with moving out of the family home, starting employment, continuing into higher education etc.

***Paragraph 75***

We suggest highlighting the importance of peer support/peer counselling, and that States should support disabled people’s organisations to provide such services. Peer support/peer counselling is key to facilitating independent living, especially during the process of deinstitutionalisation.

***Paragraph 80***

We suggest including a reference to disability hate crime, and the importance of recognising disability as one of the grounds in the relevant legislation (alongside race, gender, sexual orientation etc.). Disability hate crime is on the rise is many countries and it is important that both States and disabled people are aware of it, and know how to tackle it.

***Paragraph 84***

We suggest including working with health care professionals, whose views and misconceptions are often a major barrier to disabled people living independently. In many cases, it is the health care professionals that encourage parents of disabled children to place them into institutions.

***Paragraph 85***

We suggest adding to the sentence ‘De-institutionalisation also entails …’ the closure of special schools.

***Paragraph 92***

We suggest adding a sentence about the importance of collecting qualitative information about different services, for example about the level of choice and control disabled people have over a specific service. This would include collecting data from disabled people – ideally collected by other disabled people as experts by experience - regarding their satisfaction with accessibility, the support they receive, their ability to live independently and to fully participate in society etc.

***Paragraph 94***

We suggest adding the following:

* To subparagraph d: Special attention should be paid to disabled people with the highest support needs currently in institutions, who should not be left behind in the process of deinstitutionalisation. By starting the process of deinstitutionalisation with those with the highest support needs, States will more easily support all other disabled people to live independently in the community.
* A new subparagraph on the need to prevent institutionalisation of disabled children by the lack of family- and community-based support services.
* A new subparagraph on the need to collect disaggregated data, in order to be able to monitor progress in implementation of Article 19.
* A new subparagraph about the need to consult disabled individuals – in addition to representative organisations - in relation to any decisions that concern them. This to underline the fact that disabled people have many different identities (for example, ethnicity, race, sexual orientation, sex, gender etc.), and not all are represented by mainstream disability organisations.

## Provisions that adequately support independent or community living

***Paragraph 8***

We welcome the clarification that Article 19 refers to all persons with disabilities, irrespective of the support required. Many disabled people are perceived as ‘incapable’ of living independently, and it is important States understand that all disabled people must be supported to live in the community (and therefore covered by deinstitutionalisation strategies, prevention programmes etc.).

***Paragraph 20***

Regardless of the ‘level of intellectual capacity, self-functioning or support requirement’, people have the right to live in the community. Similar to the point above, it is key that independent living support is adequately resourced, so that people with the highest support needs are able to live in the community. In fact, research shows that people with the highest support needs should be the first to move into the community in the process of deinstitutionalisation.

***Paragraph 23***

Children with disabilities, adults and older persons with disabilities are rights holders under Article 19. Based on ENIL’s research, a number countries do not provide personal assistance to children or older people with disabilities. It is key that States Parties put in place support that follows individuals through different stages of life, and that it allows disabled people to access personalised support as they transition from childhood into adulthood, and from adulthood into old age. This would prevent disabled people from falling through gaps in the system, and losing their independence once they reach the age of 65, for example.

***Paragraphs 24 to 26***

We welcome discussion about ‘choice’ and the recognition that disabled people’s choices are often limited by various factors. There is a direct correlation between these paragraphs and Paragraph 47, referring to choice ‘to live in institutional care settings’, which we suggest should be deleted from the GC.

***Paragraph 50***

We welcome the fact that the obligation to protect also covers ‘support services not provided directly by States Parties’. This is important, as many institutions are run by private providers, such as the church or charities, and are excluded from deinstitutionalisation strategies.

***Paragraph 53***

We welcome the recognition that the families are not a replacement for support. Especially in times of austerity, families are expected to take up caring duties, regardless of whether this is in line with disabled people’s preferences. When it comes to disabled children, personal assistance should be available, so that parents can work and spend time with their other children, and in general to have a better work life balance. Accessible childcare in mainstream settings is also key for disabled children, and is the first step towards independent living and social inclusion.

*Contact person: Ines Bulic Cojocariu,* [*ines.bulic@enil.eu*](mailto:ines.bulic@enil.eu)

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1. ENIL uses the term ‘disabled people’, rather than ‘persons with disabilities’ or ‘people with disabilities’, to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability. [↑](#footnote-ref-1)
2. See: <http://enil.eu/news/enils-submission-for-the-day-of-general-discussion-on-article-19/> [↑](#footnote-ref-2)
3. See: <http://enil.eu/news/enil-publishes-report-on-the-barriers-to-independent-living-across-the-globe/> [↑](#footnote-ref-3)