Draft General Comment No. 6 on Article 5 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. We work with disabled people[[1]](#footnote-2) across impairment groups, 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 (EEG). 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 (GC) on Article 5 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Access to the right to equality and non-discrimination are key to disabled people living independently and being including in the community, and we welcome the fact that the draft GC recognises this link.

ENIL’s submission focuses mainly on paragraphs 65 – 69 of the draft GC, which in our belief should go beyond what is already stated in the General Comment No 5 on Article 19 CRPD.

## Examples of discrimination related to Article 19 CRPD

General Comment on Article 5 CRPD must acknowledge that discrimination in any part of life will negatively impact on disabled people’s ability to live independently. Whether it is discrimination in education, employment, or access to justice – disabled people are much less likely to actively participate and be included in the community.

It is positive that the draft GC sets out several discriminatory practices disabled people are subjected to when trying to access their right to live independently to live in the community. This includes discriminatory eligibility criteria for accessing support services, discrimination in access to housing, and unequal access to mainstream services. It is also acknowledged that decentralisation can lead to the so-called postcode lottery.

ENIL considers it important to add other examples, in order to make a stronger link between discrimination and inability to live independently. The examples provided below have been highlighted in ENIL’s report [Addressing Barriers to Independent Living Across the Globe](http://enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently_FINAL.pdf) (2017). For example:

* **Multiple discrimination:** Special attention should be paid to planning and implementing measures to address additional barriers disabled people face, due to their belonging to one or more social group. For example, barriers related to the person’s race, ethnicity, age, gender identity, sexual orientation, religion, language, social status, and other characteristics.
* **Discrimination against migrants:** Conditions for access to social protection for disabled migrants can be discriminatory, requiring them to wait longer than other migrants before being allowed to access support.
* **Discrimination against users of personal assistance and sign language:** Disabled people can be discriminated in accessing financial services, for example, when such services are unwilling to deal with their personal assistants or sign language interpreters. For example, a deaf person may be unable to open a bank account with the help of a sign language interpreter, when the bank refuses to deal with anyone but the customer. Similarly, personal assistants may be unable to sign documents on behalf of their employer, even when they have the employer’s explicit permission and s/he is unable to sign a document themselves.

## Amendments to strengthen the link between discrimination and the right to independent living

* **Paragraph 21:** As mentioned in §21, discrimination incudes discrimination by association and harassment. Discrimination by association remains an important barrier to the realization of the right to live Independently and be included in the community. In some countries, disabled people are still segregated from society (for example, they can be kept locked, sometimes in inhumane conditions, and not allowed to go out) partly to protect them and their family from harassment and stigma. ENIL therefore proposes to include a link to Article 19 and the right to live in the community in §21.
* **Paragraph 66:** The way services are funded can also lead to discrimination. For example, the introduction of ‘cost ceilings’ (i.e. the amount the local authority/state will pay for someone to live in the community) can discriminate against people with the highest support needs and serve as a barrier to independent living. At the same time, they create financial incentives for the relevant authorities to provide residential care. ENIL would therefore propose to add the following to §66 “accessing support services needs to be defined in a non-discriminatory, objective way. In line with the human rights-based approach, the main focus should be on the requirements of the person, rather than the impairment or the cost effectiveness of the service.”
* **Paragraph 67:** Placement in an institution must be recognised as a form of discrimination against disabled people. At the moment, disabled people living in long-stay residential institutions can be denied access to housing in the community, because they are considered as already housed. ENIL suggests to include a clear reference to §67 that long-stay residential institutions are a barrier to living independently and being included in the community and as such a tool for exclusion and discrimination.

* **Paragraph 73:** Disabled people who are unable to contribute to the economic or social activities of the family (usually people with higher support needs), face greater discrimination. Therefore, ENIL suggests adding a paragraph after §73 with a reference to the link between adequate income and discrimination. As mentioned in Article 28 CRPD, all (disabled) people have a right to an adequate standard of living and social protection.
* **Paragraph 73:** In addition to discriminating against disabled people based on their impairment, there are other ways in which eligibility criteria can lead to unequal treatment. A common type of formal restriction is ‘means testing’, which makes the use of services conditional on income. ‘Means testing’ fails to take into account the cost of disability and may contribute to keeping disabled people in poverty, by ‘punishing’ them for having an income. The introduction of ‘workfare conditionality’ is another barrier to access to services, especially for people who find it difficult to engage in paid employment, due to attitudinal and environmental barriers and the nature of their impairment. It makes access to benefits and services conditional on preparing for or engaging in paid employment. Therefore, ENIL suggests to add a point (j) to §73 of the GC: “ensure that participating in the labour market does not impede access to assistance or support services, and vice versa, that access to assistance or support services is not conditioned on participating in the labour market”.

## Positive measures to be taken by the State Party

The draft GC rightly notes that the duty to protect includes the prohibition of discriminatory practices. However, for the GC to promote access of all disabled people to living independently in the community, it must also provide examples of positive measures that must be taken by the State Parties (as it does in relation to Articles 12 and 13 CRPD, in sections vi. and vii).

Some of the measures that should be set out **after §68** include:

* Adopt specific measures with a view to **achieving inclusion and equality in access to support, benefits and services,** in particular for persons with disabilities who experience intersectional discrimination, such as women with disabilities, children and older people with disabilities, indigenous persons with disabilities, persons with disabilities from LGBTI communities and migrants.
* Adopt a **deinstitutionalization strategy**, in order to ensure that disabled people have access community-based services, including affordable and accessible housing, and are not discriminated against by being placed in institutional care, or different types of residential care.
* Ensure that support is **funded** in a way that enables all disabled people, regardless of access needs, to realize their full rights under the Convention.
* Support disabled people to achieve the right to independent living by acknowledging the role that **personal assistants and sign language interpreters** play in facilitating access to services and facilities; in line with the definition of “reasonable accommodation” in Article 2 CRPD and Article 5 CRPD, reasonable accommodation should be understood as allowing disabled people to communicate via their personal assistants or interpreters, if necessary.
* Develop and carry out awareness and capacity building programmes, including training **to service providers, professional and public authorities** (for example government officials, social workers, medical doctors, teachers) to ensure they act in accordance with the Convention. Awareness and capacity building should be developed and implemented in consultation and with meaningful participation of representative organisations of persons with disabilities.

## Explicit mention of the General Comment No 5

We suggest adding **after §69** a sentence:

The Committee calls on States parties to be guided by its General comment No. 5 (2017) on living independently and being included in the community when carrying out measures to fulfill their obligations under Articles 5 and 19.

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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-2)