## You Call this Independent Living?

## Towards an interpretation of Article 19 that fully respects the rights of persons with disabilities

Background note to the ENIL-GRIP-OL side event during the 12th Session of the CRPD Committee in Geneva, 19 September 2014

**This background note aims to provide additional information to the side event on Independent Living, organised by the European Network on Independent Living (ENIL), GRIP (Equal Rights for All Persons with Disabilities) and Onafhankelijk Leven vzw (OL) during the 12th Session of the UN Convention on the Rights of Persons with Disabilities (CRPD) Committee in Geneva. The objective of the side event is to create a space for debate and provide recommendations to the CRPD Committee on how to interpret Article 19 (Living independently and being included in the community) of the CRPD.**

1. **Introduction**

“Independent Living is the daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have **control over their own lives**. This includes the **opportunity to make choices and decisions regarding where to live, with whom to live and how to live**. Services must be accessible to all and provided on the basis of **equal opportunity**, allowing disabled people flexibility in our daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs.”[[1]](#footnote-1)

The European Network on Independent Living (ENIL), GRIP and Onafhankelijk Leven vzw (OL) are concerned about the increasing misinterpretation of the concept of Independent Living by countries across Europe. Whether it is because of the austerity measures, vested interests or the lack of vision on how disabled people can live independently and be included in the community – the fact is that rather than making advances in the provision of independent living supports, many countries are moving towards a ‘care-based’ approach, limiting disabled people’s movement and participation in society, and relying more heavily on residential provision. This was recognised by the Council of Europe’s (CoE) Human Rights Commissioner, who noted:

“An incorrect understanding of the right to live in the community risks replacing one type of exclusion with another. Though governments increasingly recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response.

This is not merely a theoretical concern. Countries which have already closed down large-scale institutions are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively to people with disability. […] Such a solution compromises the individual’s ability to choose or to interact with and be included in the community.”[[2]](#footnote-2)

In response to these developments, ENIL has proposed a set of definitions on Independent Living, personal assistance, deinstitutionalisation and community-based services (see Annex). Their aim is to explain to those responsible for developing policies and services for disabled people the expectations of the Independent Living movement. ENIL would like to see these definitions used by the CRPD Committee when reviewing State Parties’ reports on the implementation of the CRPD, as a standard all countries should be working towards.

**2. The right to live independently in the community**

Article 19 of the CRPD sets out the right of all disabled people to “live in the community, with choices equal to others”, requiring States to enable disabled people to be fully included and participate in society. State Parties to the CRPD have the obligation to provide “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

Article 19 requires a “profound shift of philosophy, new kinds of social services and resources”[[3]](#footnote-3). Its realisation is crucial to disable people’s enjoyment of other CRPD rights. As explained in the UN OHCHR report on the right to live in the community:

“[…] achievement of independent living is critically important to the intellectual and political structure of the UN CRPD and forms a crucible through which to judge what effect the treaty has on the daily lives of persons with disabilities.”[[4]](#footnote-4)

Because its implementation is dependant on the available resources, Article 19 is subject to the so-called ‘progressive realisation’. This means that it does not have to be implemented immediately, but “within a reasonable time, with measurable progress and to an extent consistent with the maximum use of available resources”[[5]](#footnote-5). Although State Parties have a certain amount of time to implement Article 19, they should “refrain from engaging in any act or practice that is inconsistent with the present Convention” (Article 4, General obligations).

To date, the CRPD has been ratified by all but three of the European Union Member States (the Netherlands, Ireland and Finland) and by the European Union itself.

**3. Examples of misinterpretation or limiting access to the right to Independent Living**

ENIL, GRIP and OL are deeply concerned about developments in countries across Europe, which are limiting disabled people’s right to live in the community. The failure to recognise the right to Independent Living as one that should be available to all disabled people, the vested interests of institutional care providers and others, the lack of knowledge and paternalistic views of policy makers, and the slashing of social and health care budgets have resulted in:

* Increasing institutionalisation, or the lack of progress in de-institutionalisation;
* Replacing large institutions with smaller ones;
* Limiting of personal assistance and personal budgets, and other services and benefits that promote social inclusion of disabled people.

It is of concern that even those countries that have been considered leaders in providing Independent Living support, such as Sweden, Denmark and the UK are undergoing reforms, which restrict disabled people’s enjoyment of the right to live in the community.

Below are a number of examples from different countries, which highlight the threats to Independent Living. Further information and analysis will be included in ENIL’s Shadow report on the implementation of Article 19 in the European Union, which will be published on 14 November 2014.

***3.1 Increasing institutionalisation, or the lack of progress in de-institutionalisation***

* Across **Central and Eastern Europe**, at least 150 million EUR have been invested in the renovation or building of new institutions for disabled people between 2007 and 2013.[[6]](#footnote-6) Human rights abuses have since been uncovered in at least two of the EU funded institutions in Romania.[[7]](#footnote-7)
* In their Concluding observations on **Austria**, the CRPD Committee has expressed concerns about increased institutionalisation of disabled people over the last 20 years.[[8]](#footnote-8)
* Recent media reports have brought to attention the fact that at least 6,500 disabled people from **France** (both children and adults, mainly with intellectual disabilities) have been placed in the institutions across the border, in Belgium.[[9]](#footnote-9)
* In **Romania**, the former ‘placement centres’ (residential institutions) for children with disabilities have been renamed as ‘inclusive education centres’. One of such centres is a residential institution accommodating 50 infants, children and young adults with disabilities.[[10]](#footnote-10)
* In the **United Kingdom**, a recent report suggested renaming residential care as ‘housing with care’, in response to negative perceptions to residential care among disabled and older people.[[11]](#footnote-11)

***3.2 Replacing large institutions with smaller ones***

* In **Bulgaria**, the process of de-institutionalisation is largely understood as the moving of people from institutions into small group homes. Although living conditions in the new establishments are better, the staff tend to maintain a patronising attitude towards people in their care and residents lack many of the basic freedoms. For example, in Lukovit, the residents of a small group home ENIL is in contact with, must submit a written request to go out, specifying the reason and when they will return.[[12]](#footnote-12)
* In **Denmark**, a country which abolished institutions in 1998, disabled people are increasingly accommodated in residential establishments accommodating large numbers of people (typically 30 – 60) and isolated from the community. Concerns about this practice have been raised by the CoE Human Rights Commissioner in his report on Denmark.[[13]](#footnote-13)
* In **Croatia**, people with intellectual disabilities or mental health problems are placed in so-called ‘family homes’, accommodating up to 20 people and run by private individuals, and ‘foster families for adults’, without their consent and with limited opportunities to participate in the community. The Government consider these services as community-based alternatives to institutional care.[[14]](#footnote-14)
* In **Hungary**, ‘living centres’ for 25 disabled residents are foreseen as part of the country’s de-institutionalisation reform.[[15]](#footnote-15)

3.3 ***Limiting of personal assistance and personal budgets, and other services and benefits that promote social inclusion of disabled people***

* The 2012 EFC report[[16]](#footnote-16) on the impact of European governments’ austerity plans on the rights of disabled people identified the following restrictions on the right to Independent Living: the closure of the Independent Living (ILF) in the **United Kingdom**, worth 359 billion GBP to new applicants in 2010, and the proposed closure to all ILF users in 2015; postponement of the introduction of personal budgets and a 37% cut in the budget for assistive devices in **Portugal**; the proposal to cut 90% of personal budgets in **Netherlands** in 2014, which has since been postponed; failure to grant any ‘environmental control devices’ in **Ireland** for over two years.
* The same report pointed to the increasing institutionalisation of disabled people in **Ireland, Portugal, the Netherlands** and the **UK** as a direct result of the austerity measures. In Portugal, for example, legislative changes increased the maximum number of residents per bedroom and reduced the square metres per residents in residential care

**4. Recommendations**

ENIL, GRIP and OL urge the CRPD Committee to remind the State Parties of their obligations under the CRPD, using all means at its disposal. This is crucial to stop further threats to Independent Living and to facilitate the enjoyment of the right to live independently in the community by all disabled people.

The key steps that must be taken by State Parties to the CRPD to ensure the implementation of Article 19 include:

* **Disability policy based on a human rights approach.** Countries must move away from the “one size fits all” and the care-based approach, and adopt policies in line with the CRPD, which reinforce the key principles of Independent Living – self-determination, freedom of choice and control over one’s life and life style. There needs to be a change in disability policy, which must move away from institutional care. There is no place in the human rights based disability policy for institutions (large or small). New laws and regulations should be monitored, in order to ensure that they have a positive effect on disabled people’s ability to live independently in the community.
* **Re-direction of available resources to the service users.** Budgets for the support of disabled people should primarily go to service users, and not to service providers. Without further delay, governments should adopt clear plans and budgets, to ensure that adequate support and assistance will be provided to all disabled people. Peer support and support provided by user-led organisations should be adequately financed, so that it is available to disabled people who need help in managing their personal assistance and other support services.
* **Personal assistance for all.** All disabled people, regardless of their age, type of impairment or material status must be able to access personal assistance. Personal assistance should be based on the principles in the *Model National Personal Assistance Policy*, formulated in 2004 by the European Center for Excellence in Personal Assistance (ECEPA).[[17]](#footnote-17) There is no evidence to show that personal assistance or other community-based services are more expensive than institutional care, if the comparison is based on the needs of the service users and the quality of support.[[18]](#footnote-18) To this we should also add the opportunity to take part in and contribute to their communities and the society.
* **Improved understanding of Independent Living terminology.** The realisation of Article 19 of the CRPD depends on the common understanding of how all disabled people can live independently, included in the community. To this end, the CRPD Committee should promote definitions of key Independent Living terms, such as de-institutionalisation, personal assistance and community-based services among governments and other stakeholders, and ensure that they are correctly understood.

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**Annex: ENIL’s key definitions on Independent Living**

**These definitions are intended for use in the development of guidelines, policy and legislation at the European Union level, Member State level and local level. Their aim is to give decision makers clear guidance for the design and implementation of disability policy. They have been developed to prevent the manipulation and the misuse of our language for the development of policies that are counter-productive to Independent Living.**

The concept of Independent Living (IL)[[19]](#footnote-19) is much older than the UN Convention on the Rights of Persons with Disabilities (‘CRPD’). It has played a key part in the drafting of the CRPD, especially Article 19, but is also underpinning other articles, none of which can be realised without IL. Article 19 sets out the right to choose where, with whom and how to live one’s life. This allows for self-determination upon which IL is based. There is a continuous debate on *independence* vs. *interdependence*; ENIL considers that all human beings are interdependent and that the concept of IL does not contravene this. IL does not mean being independent from other persons, but having the freedom of choice and control over one’s own life and lifestyle.

**Independent Living (IL):**

IL is the daily demonstration of human rights-based disability policies. IL is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life. IL requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that IL is for all disabled persons, regardless of the level of their support needs.

**Personal Assistance (PA):**

PA is a tool which allows for IL. PA is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. PA should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. PA allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

**Deinstitutionalization (DI):**

DI is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to IL. Effective DI occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of DI is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. DI is also about preventing institutionalization in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

**Community-based Services (CBS):**

The development of CBS 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. CBS 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 IL and, if already provided, must exist alongside other genuine, adequately funded IL options.

*Adopted November 2012 by the ENIL board*

1. See ENIL’s key definitions on Independent Living, available at : <http://www.enil.eu/policy/> [↑](#footnote-ref-1)
2. See *The right of people with disabilities to live independently and be included in the community.* Issue Paper commissioned and published by Thomas Hammargerg, Council of Europe Commissioner for Human Rights, page 13, available at: <https://wcd.coe.int/ViewDoc.jsp?id=1917847> [↑](#footnote-ref-2)
3. See UN OHCHR Regional Office for Europe, *Getting a Life: Living Independently and Being Included in the Community,* page 30, available at: <http://www.europe.ohchr.org/documents/Publications/getting_a_life.pdf> [↑](#footnote-ref-3)
4. *Ibid,* page 24 [↑](#footnote-ref-4)
5. *Ibid,* page 31 [↑](#footnote-ref-5)
6. See ENIL-ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living,* available at: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf> [↑](#footnote-ref-6)
7. See Mental Disability Advocacy Centre, <http://mdac.info/en/content/european-commission-funding-disability-segregation-and-abuse-breaches-international-law> [↑](#footnote-ref-7)
8. See: <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en> [↑](#footnote-ref-8)
9. See, for example, <http://www.lemonde.fr/sante/article/2014/01/03/la-dignite-due-aux-handicapes-mentaux_4342696_1651302.html?xtmc=handicap&amp;xtcr=14> [↑](#footnote-ref-9)
10. See Report by Niels Muiznieks, Council of Europe Commissioner for Human Rights, following his visit to Romania, from 31 March to 4 April 2014, available at: <https://wcd.coe.int/ViewDoc.jsp?id=2208933&Site=COE> [↑](#footnote-ref-10)
11. See the Commission on Residential Care report, available at: <http://www.demos.co.uk/files/Demos_CORC_report.pdf?1409673172> [↑](#footnote-ref-11)
12. Information provided by the Centre for Independent Living Sofia [↑](#footnote-ref-12)
13. See Report by Niels Muiznieks, Council of Europe Commissioner for Human Rights, following his visit to Denmark, from 19 to 21 November 2013, available at: <https://wcd.coe.int/ViewDoc.jsp?id=2145355> [↑](#footnote-ref-13)
14. See Human Rights Watch submission to the United Nations Committee on the Rights of Persons with Disabilities regarding Croatia, 25 August 2014, available at: <http://www.hrw.org/news/2014/08/25/human-rights-watch-submission-united-nations-committee-rights-persons-disabilities-r> [↑](#footnote-ref-14)
15. See ENIL-ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living,* available at: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf> [↑](#footnote-ref-15)
16. See EFC, *Assessing the Impact of European Governments’ Austerity Plans on the Rights of People with Disabilities, Key Findings*, available at: <http://www.efc.be/programmes_services/resources/Documents/Austerity2012.PDF> [↑](#footnote-ref-16)
17. See <http://www.independentliving.org/docs6/ratzka200410a.html> [↑](#footnote-ref-17)
18. See Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, available at: <http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf> [↑](#footnote-ref-18)
19. Independent Living derives from the Independent Living movement that started in the late 1960s in Berkeley, California as a grassroots movement. [↑](#footnote-ref-19)