ABOUT US

The Centre for Disability Law and Policy (CDLP) at National University of Ireland, Galway was formally established in 2008 and works in pursuit of equal opportunities and social justice for persons with disabilities in Ireland and around the world. Since its establishment, the CDLP has organized and participated in a number of key events regarding disability law reform. The CDLP’s operating philosophy is ‘scholarship in action’ which entails research that addresses the problems that ordinary citizen’s face and providing practical policy solutions. In the course of our work we have made submissions to national and international bodies advocating for policies and laws that best facilitate the free and full exercise of rights for people with disabilities.

INTRODUCTION

The CDLP welcomes the opportunity to provide comments on the Committee on the Rights of Persons with Disabilities (hereinafter, “CRPD Committee”) draft general comment Nº 5 on the right of persons with disabilities to live independently and be included in the community (Article 19). The CDLP appreciates the draft general comment’s strong recognition of the right to live independently in the community of persons with disability, restoring personhood through the guarantee of human rights.

SECTION I. INTRODUCTION

PARAGRAPH 14

**Proposed text of the amendment:**

(l) Lack of sufficient evidence base to design effective strategies, action plans and allocation of resources giving effect to Article 19.

SECTION III. OBLIGATIONS OF STATES PARTIES

PARAGRAPH 47

We, from the CDLP believe that paragraph 47 of the Draft does not fully reflect Article 19 or the CRPD as a whole.

Article 19 takes as its starting point the institutionalisation that people with disabilities have experienced. This experience violates human rights, as affirmed by the CRPD Committee in several Concluding Observations.[[1]](#footnote-1)

The experience of institutionalisation is one which persons with disabilities have described as inherently lacking in choice – and one which typically occurs due to the absence of support to live well in the community.[[2]](#footnote-2) There is significant research evidence to demonstrate that no person ‘chooses’ to live in an institution if other appropriately resourced options are available in the community and if the person has been properly supported to try different options.[[3]](#footnote-3) Since it was the State which was responsible for institutionalising persons with disabilities in the first place, it is now the responsibility of the State to end institutionalisation. Further, it is well established in international human rights law that the right to choose is not limitless – for example, human rights norms do not recognise an individual’s right to choose to be a slave, to be trafficked or to undergo torture, cruel, inhuman or degrading treatment.[[4]](#footnote-4)

This paragraph of the draft GC on article 19 could allow States parties to the CRPD to justify restoring institutions and therefore, moving backwards and against the CRPD Committee’s statements. “No dynamic of reform, no matter how well intentioned, could then gain traction over time. It would be much preferable to set a goal of securing personalised living arrangements that allow for the optimum possibility of community inclusion and engagement. Exceptions should be avoided in order to preclude them swallowing the rule. This does not mean that everything has to happen at once – that’s why international law endorses the concept of ‘progressive achievement.’ But it is to say that no ‘progressive achievement’ can ever realistically happen if the new rule (independent living) is constantly dragged back by exceptions that will only perpetuate isolation.”[[5]](#footnote-5)

PARAGRAPH 65

**Proposed text of the amendment:**

65. Often, the right to live independently and be included in the community is violated not because resources are not available, but because they have been misallocated. Misallocation of resources into institutionalized support services is a clear violation of article 19.

States parties must take deliberate and immediate steps to reallocate funding into independent and community living programs and phase out funding for institutional care. States parties must have a widely strategic vision for the transition from institutional care to community living. In this sense, the investments should be seeking to eliminate institutional care rather than invest in new institutional care homes. Doing so requires an analysis on the situation of persons with disabilities and therefore an understanding of what measures are needed to realise community living.[[6]](#footnote-6) States parties have to consult with organizations with persons with disabilities according also with article 33 of the CRPD.

SECTION IV. RELATIONSHIP WITH OTHER PROVISIONS OF THE CONVENTION

PARAGRAPH 72

A similar paragraph is needed for older persons and for older persons with disabilities. Innovative housing solutions such as co-housing and the use of assistive devices and technology should be addressed in this sense.

PARAGRAPH 84

**Proposed text of the amendment:**

84. The right to independent and community living is intimately linked with the right to family for children and parents with disabilities (art. 23). If community based support and services are not in place, this may create financial pressures and constraints for the families of persons with disabilities; the rights enshrined in article 23 of the Convention are essential to prevent children from being taken away from their families and being institutionalized as well as to support families in community living. In some countries children are institutionalized to provide special education, or allegedly specialist healthcare and therapy or to protect them from abuse and neglect; but whilst doing this, they are denied their right to family life and are often exposed to greater risk of abuse or neglect. States parties should provide information, guidance and support to families in upholding their children’ rights and promote inclusion and participation in the community so that families are in a better position to contribute to independent and community living.

PARAGRAPH 92

**Proposed text of the amendment:**

Data and information should be disaggregated systematically (art. 31) by disability across all sectors including with respect to housing, living arrangements, social protection schemes as well as access to community support and services. It is important that indicators reflect the particular circumstances in every State party, taking into account social environments. One of the core elements of the Sustainable Development Goals is the clear position on data disaggregation, the Washington Group Short set of questions is recommended as a methodology to disaggregate data by disability. The information should allow for analyses on how de-institutionalization and transition to community support have progressed. To be effective, planned measures in strategies and funding programmes for deinstitutionalization must be based on sufficient evidence including, but not limited to, an assessment of local situation and considering territorial differences, rural and urban areas, availability and access to quality mainstream services. Disaggregate data about persons living in institutions and persons with support needs living in the community.

SECTION V. IMPLEMENTATION AT THE NATIONAL LEVEL

PARAGRAPH 94 (g)

**Proposed text of the amendment:**

(g) Design clear and comprehensive legislative and policy guidelines and allocate sufficient financial resources for the construction of accessible housing units, small scale community based health and social infrastructure, public buildings and public spaces and transport along with an adequate time frame for their implementation and sanctions for violations by public or private authorities. Such guidelines should be mandatory and address the issues of accessibility and responsiveness to the requirements of all persons with disabilities. States parties must identify a unit of government that will be responsible for monitoring compliance with such guidelines.

1. See for example the following Concluding Observations of Czech Republic (CRPD/C/CZE/CO/1) 15th May 2015 para 39; Lithuania (CRPD/C/LTU/C/1) 20 April 2016 para 40; China (CRPD/C/CHN/CO/1) 14 November 2012 para 32; Argentina (CRPD/C/ARG/CO/1) 22 October 2012 para 34; Croatia (CRPD/C/HRV/CO/1) 15 May 2015 para 29-30; Spain (CRPD/C/ESP/CO/1) 19 October 2011 para 39, among others. [↑](#footnote-ref-1)
2. See for example the following Concluding Observations of Gabon (CRPD/C/GAB/CO/1) 2 October 2015 para 44; Kenya (CRPD/C/KEN/CO/1) 30 September 2015 para 37; Slovakia (CRPD/CO/SVK/CO/1) 18 April 2016 para 55; Lithuania (CRPD/C/LTU/C/1) 20 April 2016 para 39; Spain (CRPD/C/ESP/CO/1) 19 October 2011 para 39; Czech Republic (CRPD/C/CZE/CO/1) 15 May 2015 para 39; Germany (CRPD/C/DEU/CO/1) 13 May 2015 para 41; New Zealand (CRPD/C/NZL/CO/1) 30 October 2014 para 39; Denmark (CRPD/C/DEN/CO/1) 29 October 2014 para 42; Belgium (CRPD/C/BEL/CO/1) 27 October 2014 para 32, among others. [↑](#footnote-ref-2)
3. See for example, Commissioner for Human Rights, Council of Europe (2012), The right of people with disabilities to live independently and be included in the community. Council of Europe Publishing. Available at:https://www.coe.int/t/commissioner/source/pre-ms/RightsToLiveInCommunity-GBR.pdf [Accessed 30 June 2017] and, Lilia Angelova-Mladenova (2017). The Right to live Independently and be included in the Community Addressing Barriers to Independent Living across the Globe. European Network on Independent Living. Available at: http://enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently\_FINAL.pdf [Accessed 30 Jun. 2017]. [↑](#footnote-ref-3)
4. See for example, Universal Declaration of Human Rights (Article 4, 5 & 7); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (article 2); Convention on the Elimination of All Forms of Racial Discrimination (Article 3). [↑](#footnote-ref-4)
5. Gerard Quinn and Suzanne Doyle (2012), Getting a life: Living independently and being included in the community. Office of the United Nations High Commissioner for Human Rights, Regional Office for Europe, p.28. [↑](#footnote-ref-5)
6. See ENIL-ECCL (2016), Working Together to Close the Gap Between Rights and Reality: A report on the action needed to ensure that European Structural and Investment Funds promote, not hinder, the transition from institutional care to Community Living. European Network on Independent Living – European Coalition for Community Living. Available at: http://www.enil.eu/wp-content/uploads/2016/06/Working-Together-to-Close-the-Gap.pdf [Accessed 30 Jun. 2017]. [↑](#footnote-ref-6)