



European Network on Independent Living (ENIL)

<https://enil.eu/>

Focal point: Rita Crespo Fernandez, Human Rights Officer, rita.crespo-fernandez@enil.eu

Chapeau

The right to independent living for disabled people, as enshrined in article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), is an obligation of all Member States to the Convention. Living independently means making your own choices and having control over your life, and it is achieved by having access to community-based services and support, in an accessible environment.

However, disabled people across the world still live in segregation, whether in institutions or at their own homes and communities, without access to the same spaces as non-disabled people. Political participation remains limited, while there are still investments in segregated environments.

The right to independent living must be ensured in all actions, to prevent segregation and exclusion, and to make sure all disabled people can have choice and control over their lives, as described in [General Comment n°5](#) and the CRPD [Guidelines on Deinstitutionalisation, including in emergencies](#).

Chapter I. Sustainable development and financing for development

The right to independent living is insufficiently financed in development cooperation. In low and middle-income countries, community-based services and support remain underfinanced and underdeveloped, which translates into a lack of autonomy and agency, and can be a driver of institutionalization in some contexts. Other obstacles include denial of legal capacity, inadequate social protection schemes, lack of deinstitutionalization strategies, and persistent stigma and negative attitudes.

However, responses have long been inadequate. Donors do not invest enough on necessary services and support for disabled people, and instead keep investing in segregated settings such as institutions, small group homes, sheltered workshops, or special education.¹

Responses to the increased need for long-term care and the disproportionate burden of care

¹ European Disability Forum and European Network on Independent Living (2022). *Role of the European Union funding in supporting deinstitutionalisation around the world: A Call for Change*, available at [ENILEDI Global Report Final for Publication 140222](#)

and support of women, fail to comply with the right to independent living and to take into account the views of disabled people, promoting instead the medical model of disability.

Donors must follow the “do no harm” principle by ensuring that their investments do not fund institutions and other segregated settings, as defined in the CRPD [Guidelines on deinstitutionalization, including in emergencies](#). Instead, investments should fund community-based services and direct support, such as personal assistance and assistive technology, and ensure the accessibility of mainstream services such as health, education and employment.

Chapter II. International peace and security

Conflict has a disproportionate impact on disabled people, due to a heightened risk of loss of life and injury, disruption of services, and lack of access to evacuation and humanitarian aid. Particularly, those living in institutions are at an increased risk of neglect. Conflict may also lead to an increase of institutionalisation to those displaced, as the host authorities may lack capacity to integrate disabled people into their social protection system. In addition, during and after conflict, deinstitutionalisation is seldom prioritized, despite the urgency, due to competing priorities. Instead, recovery efforts may be used to finance the re-building of destroyed institutions.

In Europe, the invasion of Ukraine by Russia has been proof of the need to prioritise deinstitutionalisation in emergency contexts. Pre-existing high rates of institutionalisation of disabled people, including children, led to disabled people being abandoned in institutions, to the impossibility to access humanitarian aid, and difficulties to be evacuated of war zones. When disabled people living in institutions were evacuated, the Ukrainian government requested that they stay together in host countries. As host countries did not have the capacity to do this, they have been returned to war zones, even in the case of disabled children.

In times of conflict, the CRPD [Guidelines on deinstitutionalisation, including in emergencies](#), must be observed. Deinstitutionalisation must remain a priority of all parties, to ensure that disabled people are not disproportionately impacted.

Chapter III. Science, technology and innovation and digital cooperation

Technology has great potential to improve disabled people’s access to education, employment, the built environment, etc. In particular, assistive technology is a form of support that has great impact on disabled people’s lives. New technological developments can reduce the costs and make technology better fitted to the needs of disabled people.

However, experiences during the pandemic show that even if technological advancements can be beneficial, we must not replace all in person options by digital solutions. For instance, the denial to pay in cash in shops led to people under guardianship in France to not be able to do their shopping independently, as they cannot own credit cards. Education was particularly impacted, as a result of the lack of accessible materials and support for disabled children.

In addition, we have observed that in the European Union, projects that are segregating for disabled people can be funded under a justification of their innovative nature, such as promoting energy efficiency or technological advances.

Therefore, actions must promote the use of technology to advance the rights of disabled people, but moving from “digital first” solutions to using technology when it does create positive impact, and ensuring in person options remain. Innovation should never be used to harm or segregated disabled people.

Chapter IV. Youth and future generations

Young disabled people are diverse, as disability intersects with gender, ethnicity, migrant status, religion or being LGBTQ+. Intersectional discrimination can further limit their opportunities for education, employment, leisure and political participation, putting at risk their independent living. But diversity is also valuable. Ensuring that young disabled people, in all their diversity, are part of political processes, and can thrive in society, can not only open the doors for many other marginalized communities to experience the same success, but also to contribute to the future of the movement with new leaders coming on board. Meaningful participation of disabled youth is not a token, but the key for positive change.

Chapter V. Transforming global governance

Development cooperation projects are not sufficiently involving disabled people and their representative organisations as equal partners in projects that affect them. When they are consulted, this is done sporadically, but they do not have meaningful roles and cannot effectively make decisions. Even when Disabled People's Organisations (DPOs) try to lead projects, they often lack the capacity to apply and cannot compete with larger organisations. Lack of access to inclusive education for disabled people in low and middle-income countries further exacerbates this issue. ²

Consultations of relevant policies also fail to meaningfully engage disabled people and their representative organisations. When authorities do run consultations, they often involve national umbrellas of DPOs, which do not always represent the diversity of disabled people.

There must be full involvement of disabled people and DPOs, as defined in [General Comment n°7](#), in the planning, implementation and evaluation of relevant projects. Capacity building is key to address inequalities and power imbalances, while ensuring that all processes are accessible.

² European Disability Forum and European Network on Independent Living (2022). *Role of the European Union funding in supporting deinstitutionalisation around the world: A Call for Change*, available at [ENILEDF DI Global Report Final forPublication 140222](#)