**Position Paper on the Multiannual Financial Framework 2028 - 2034 discussions**

Response of the European Network on Independent Living to the “Public consultation on the next MFF: Implementing EU Funding with Member States and regions”

*5 May 2025*

# **Introduction**

As the Multiannual Financial Framework 2021-2027 approaches the end, the European Union is reflecting on what the next budgetary period should look like. In this context, it has launched a public consultation on the next Multiannual Financial Framework 2028 – 2034.

This response, prepared by the European Network on Independent Living – ENIL, is based on the lessons learned by ENIL from the current and previous budgetary periods, with the objective to ensure better use of the European Union (EU) funds to address social inequalities across the EU and beyond.

ENIL has been monitoring the use of EU Funds since 2007, in relation to how they are supporting or inhibiting implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD; ratified by the EU and all Member States). Our work has focused on monitoring investments in institutions for persons with disabilities, as well as projects that improve the availability of community-based services (such as personal assistance). ENIL has published numerous reports on the topic, has submitted many complaints and carried out other legal and advocacy activities. An overview the relevant activities is available from here.[[1]](#footnote-1)

In the Concluding observations on the European Union by the Committee on the Rights of Persons with Disabilities[[2]](#footnote-2), published on 21 March 2025, the Committee raised concerns about the continued misuse of EU funding “for the construction and maintenance of institutional facilities, including small group homes, in Member States” and the lack of policies and investments aimed at “development of support measures in the community”. The Committee also criticised the current monitoring system for EU funds, which fails to “effectively ensure compliance with the obligations under the Convention” and denies organisations of persons with disabilities “access to judicial oversight processes”.

**The Committee provided the following recommendations to the European Union, which must be taken into consideration when drafting the rules governing the next Multiannual Financial Framework:**

* Ensure that no EU funding, including the Recovery and Resilience Facility and the Neighbourhood, Development and International Cooperation Instrument, is used for the construction or maintenance of institutional facilities, including small group homes, and shape the Multiannual Financial Framework accordingly. (para 49b)
* Ensure that the post 2027 Cohesion Policy Legislation explicitly bans the use of EU funds for the construction and maintenance of institutional facilities, including small group homes, that the Disability Strategy 2021-2030 and its action plans for the period 2025-2030 comply with the obligations set out in the Committee’s General comment No.5, and that the European Union conduct and publish an impact analysis of previous funding, in close consultation and active involvement of persons with disabilities through their representative organizations. (para 49c)
* Strengthen monitoring and complaint mechanisms of the allocation of EU funds, by enhancing independence of monitoring committees at the national level, ensuring monitoring by national human rights institutions, persons with disabilities and their representative organizations, in the allocation of EU funds for disability-specific purposes, ensure effective access to justice for persons with disabilities and their representative organizations against the allocation of EU funds by Member States in violation of the Convention, and use its powers, such as infringement procedures, against Member States failing to implement these measures. (para 49f)
* Adopt unambiguous definitions of community-based services, including personal assistance, to improve targeting of investments, and collect and publish disaggregated data on the services provided and persons with disabilities utilizing them; prioritize investments for the development of accessible and affordable housing for persons with disabilities, personal assistance, centers for independent living, peer support and other types of individualized support respecting the will and preference of persons with disabilities. (para 49g)[[3]](#footnote-3)

With the Committee’s recommendations in mind, this position paper makes concrete proposals which should be integrated in the upcoming EU budgetary framework. In line with the Committee’s recommendation on the definition of the key terms, a glossary is included at the end of the document.

# **Positive evolution in the 2021-2027 period**

The current EU budget 2021-2027 adopted specific legislative measures to promote deinstitutionalisation of persons with disabilities through EU funding. In addition, there are several soft policy instruments that support this process.

The Common Provisions Regulation for the period 2021-2027[[4]](#footnote-4) includes the thematic enabling condition on the transition from institutional community-based care, in addition to a horizontal enabling condition on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). At the moment, all Member States are deemed to be fulfilling these conditions. The European Social Fund Plus Regulation also includes the objective to promote the transition to community-based living.

The European Union’s Strategy for the Rights of Persons with Disabilities 2021 – 2030[[5]](#footnote-5) identifies “developing independent living and reinforcing community-based services” as one of the three priorities for the EU. It states that the “Commission will support national, regional and local authorities in their efforts for deinstitutionalisation and independent living, including through the 2021 – 2027 shared management funds”.

The European Union’s Strategy on the Rights of the Child and the Child Guarantee[[6]](#footnote-6) focus, among other, on children in institutional care, and aim to facilitate the development of community-based and family-based care in the Member States. They stress the importance of prevention services for vulnerable children and families, with the aim of preventing the placement of children in institutional care. There is recognition that these objectives must be sufficiently funded by a range of EU funds.

The Guidance on independent living for persons with disabilities to live independently and to be included in the community[[7]](#footnote-7) was published by the European Commission in November 2024, to ensure that the Managing Authorities comply with the requirements of the UNCRPD. The Guidance is based on the UNCRPD, the General Comment 5[[8]](#footnote-8) and the Guidelines on deinstitutionalisation, including in Emergencies[[9]](#footnote-9).

The Guidance highlights specialised support services, such as personal assistance, and mainstream services, such as accessible housing and inclusive education, that should be funded by the EU. It advises against funding institutions for persons with disabilities or replacing large institutions with small group homes.

Some Operational Programmes (OPs) for 2021 – 2027 translated these principles into the planned investment measures. For example, a Portuguese OP includes references to the horizontal principles of the Charter, the UNCRPD (including recommendations of the CRPD Committee), and the EU Strategy on the Rights of Persons with Disabilities. Some OPs clarify that they do not support any investments that contribute to segregation or that promote backsliding in the process of deinstitutionalisation, or to the need to promote deinstitutionalisation efforts, the development of community-based services, and the obligation to not promote segregation and avoid reversing deinstitutionalization efforts. [[10]](#footnote-10)

Among the good practices from the current programming period is the programme on personal assistance, the Independent Living Support Model (MAVI, per its initials in Portuguese)[[11]](#footnote-11), supported by the European Social Fund Plus. MAVI has been implemented by the Centers of Independent Living in Portugal and has had a positive impact on the right to independent living of persons with disabilities. Several other OPs refer to the promotion of community-based services, accessibility of the environment, investments in inclusive education for disabled learners, the reduction of the employment gap, the empowerment of civil society, or the improvement of participation of persons with disabilities in society. Such good practices should be continued and upscaled in the future EU budget.

# **Areas for improvement in the implementation of EU funds**

Despite the positive effect of the current funding period, the European Court of Audits concluded that “the impact of EU actions supporting persons with disabilities was limited”. In relation to the use of EU funds, its 2023 Special report[[12]](#footnote-12) stated:

“We found that the Commission’s monitoring framework was not designed to provide information on the extent to which EU funding helped improve the situation for persons with disabilities in both the 2014-2020 and 2021-2027 programme periods. The cohesion policy programmes do not include a category of expenditure concerning support for persons with disabilities. The 2021-2027 EU legislation introduced new requirements concerning the horizontal enabling condition on the implementation of the UN Convention and the European Semester process. However, these may only have a limited impact on improving the targeting of EU funding to the needs of persons with disabilities.”

In practice, together with other public or private sources of funding, EU funds have in some Member Stated led to an increasing number of persons with disabilities being placed in institutional care[[13]](#footnote-13). This is also the case for children with disabilities and for older people in need of support[[14]](#footnote-14). Transinstitutionalisation, or moving people from large to smaller institutions (such as small group homes), has become particularly widespread. In numerous instances, these segregated settings have received EU funding[[15]](#footnote-15). This means that, even where there is a reported decrease in the number of people in institutions, it is likely due to children or adults with disabilities being placed in other forms of residential care.

ENIL has identified five key areas for improvement for the next MFF, which are explained in this section.

## Guarantee sufficient support for the development of community-based services for persons with disabilities and deinstitutionalisation, in line with the UNCRPD

EU funds provide an opportunity to reverse the trend of continued and increased placement of children, adults with disabilities and older people in institutions. For this to happen, new community-based services must be developed, and mainstream services, such as housing, health care, education and employment should become accessible and available to persons with disabilities.

Importantly, EU funds must not be used to build new institutions or prolong the life of existing institutions, of any size. ENIL has been consistently reporting and submitting complaints against investments of EU funds into institutions for persons with disabilities throughout the current and the previous programming periods[[16]](#footnote-16).

To get a better understanding of the projects funded by the EU with the objective of “deinstitutionalisation”, ENIL carried out an extensive analysis of the Commission’s Kohesio platform during 2024. In total, we examined 287 “deinstitutionalisation” projects in 11 countries financed by EU funds as part of the 2014 - 2020 programming period (the last period for which data is available) and found numerous examples of investments into segregated settings. There were many projects consisting of the transformation of large institutions into small group homes; for instance, an example was found in Hungary of replacing an institution for 72 persons with psycho-social disabilities with a new structure, consisting of 6 apartments with 12 persons each. In addition, we found examples of investments into large institutions, small group homes and segregated day care centers; several of these were specifically targeted at children with disabilities or older persons.

We have also witnessed Member States including investments into institutions into their plans to spend EU funds. Several Operational Programmes (OPs) for 2021 - 2027, which have been approved by the European Commission, contain plans for investments in institutions (for example, Czech Republic, Slovakia, Poland and Portugal).

The Communication from the Commission on the mid-term review[[17]](#footnote-17) includes investments in affordable housing as a specific objective. This is a welcome development, as access to housing is essential for persons with disabilities to live independently. However, without guarantees, these investments can be used towards housing that is inaccessible or segregated from the community. The incentives foreseen for the five specific objectives (i.e. closing the innovation gap, defence and security, water resilience, affordable housing, and energy transition and security) also risk that other investments, albeit essential to advance social cohesion, will be reduced.

**Recommendations for the next MFF:**

* **Include social inclusion of persons with disabilities and deinstitutionalisation as priorities for the funding instruments that will be part of the next MFF, mainstreamed across all relevant policy areas.** Ensure that deinstitutionalisation process result in opportunities for enjoyment of the right to independent living, in line with UNCRPD.
* **Increase funding for personal assistance schemes, for all those in need of such support (including children) and Centers for Independent Living,** as these are key to implementation of the right to independent living in the EU and are an alternative to institutionalisation. Importantly, incentives towards investments in the specific objectives should not lead to reductions in other essential sectors.
* **Ensure that housing built with the support of EU funds is accessible, affordable, non-segregated and in the community,** to comply with obligations under the UN CRPD and to avoid further excluding persons with disabilities and other marginalised groups from access to housing.
* **Introduce a clear prohibition in the Common Provisions Regulation and the rules governing the use of individual funding instruments of investing into any form of segregation**, including but not limited to, large and small institutions (such as small group homes), sheltered workshops, or special education settings. Such prohibition should recall Member States’ and the EU’s obligations under the UN CRPD and the EU Fundamental Rights Charter, and should be based on institutionalisation constituting discrimination against persons with disabilities.
* **Include a definition of an institution, community-based support and deinstitutionalisation**, based on the UNCRPD, its General Comments and the CRPD Committee’s Guidelines on deinstitutionalisation, including in emergencies, in the Common Provisions Regulation and the rules governing the use of individual funding instruments.
* **Ensure that there are no exceptions that would allow investments in institutions in the planning and implementation of EU funds.** Revoke any internal legal opinions that permit such investments.
* **Refer to the Commission’s Guidance on Independent Living** when drafting new rules governing the use of EU funds. In line with the partnership principle, ensure meaningful involvement of persons with disabilities and their representative organisations throughout this process.
* **Improve the collection of data about projects benefiting persons with disabilities,** ensuring they include sufficient information to identify how many people moved out of an institution, where they moved to, what support services, or housing have been funded etc. This would allow us to better understand the impact of EU funds on persons with disabilities and the right to independent living.

## Maintain enabling conditions and strengthen their implementation

The current Common Provisions Regulations contain a number of enabling conditions, which the Member States are required to fulfil to receive EU funds. Among these is the horizontal enabling condition on the implementation of the UNCRPD, which applies to all funding; and the thematic enabling condition on the transition from institutional community-based care, which is sector-specific, laying out the conditions in this area. If the conditions are not met at the time a Member State requests a payment to the Commission, the Commission will not reimburse the expenses to the Member State.

The enabling conditions are crucial in ensuring compliance with the UNCRPD and the EU Fundamental Rights Charter. If applied properly, they should prevent or interrupt investments that violate the rights of persons with disabilities and other marginalised groups.

ENIL submitted an access to documents request to the Commission in 2023 to understand the evaluation of the horizontal enabling conditions. In the response, we received a checklist used by the Commission setting out the different criteria used to assess compliance with the UNCRPD enabling condition. Member States are required to have in place:

1. Objectives with measurable goals, data collection and monitoring mechanisms.
2. Arrangements to ensure that the accessibility policy, legislation and standards are properly reflected in the preparation and implementation of the programmes.
3. Reporting arrangements for the monitoring committee regarding cases of non- compliance of operations supported by the Funds with the UNCRPD and complaints regarding the UNCRPD submitted in accordance with the arrangements made pursuant to Article 63(6)CPR.

However, due to the self-assessment of the enabling conditions by the Managing Authorities, they have failed to achieve the intended objectives. This was confirmed by the European Ombudsman in the February 2025 inquiry[[18]](#footnote-18) into how the European Commission ensures fundamental rights compliance in the context of EU funds granted to Greece for border management. The Ombudsman asked the Commission to:

“Put in place guidelines for assessing compliance with fundamental rights, notably the horizontal enabling condition relating to the Charter of Fundamental Rights (the Charter HEC), throughout the course of the programming period. **The guidelines should include the need to take into account independent sources of information in the Commission’s assessments.** As part of these guidelines, the Commission should establish criteria to determine under what circumstances it will withhold or suspend EU funds for non-compliance with fundamental rights and/or the Charter HEC, and publish these criteria.” (emphasis added)

Having reviewed the documents relating to the fulfilment of the UNCRPD enabling condition by Latvia, ENIL can confirm that the only party consulted by the Commission to establish whether the enabling conditions are being fulfilled was the Managing Authority (i.e. the relevant Ministry). Furthermore, the documents studied confirmed it was enough for the MS to have a strategy in place to fulfil the enabling condition - regardless of the quality of the strategy, the level of compliance with the UNCRPD, or whether and how it is being implemented. We have not seen any evidence of how any potential cases of non-compliance with the UNCRPD are being reviewed or what the role of organisations of persons with disabilities or independent human rights bodies is in this process.

With regard to the horizontal enabling condition relating to the Charter, the Commission has questioned its applicability when it comes to investments into institutions for persons with disabilities. In response to one of ENIL’s complaints, the Commission stated that: *“the mere fact that a given infrastructure has been financed by the Union does not mean that the Member State implements Union law”*.[[19]](#footnote-19)

**Recommendations for the next MFF:**

* **Retain the horizontal and thematic enabling conditions in the next programming period**, to ensure fundamental rights compliance of EU funds. As in the past programming period, enabling conditions must be linked to UNCRPD, the Fundamental Rights Charter, and should include the objective of deinstitutionalisation as defined in the Committee’s Guidelines on deinstitutionalisation, including in emergencies.
* **Improve the application of enabling conditions, by giving priority to independent sources when assessing Member States’ compliance.** These include civil society organisations and national human rights institutions (NHRIs), which must be involved in the assessment alongside the Managing Authorities; to ensure they have adequate capacity for this task, their involvement must be financed through technical assistance or other public funding.
* **With civil society organisations and national human rights institutions, develop new guidelines for assessing enabling conditions.** Ensure that the guidelines are publicly available, together with the results of the assessment (showing how the Member State demonstrated fulfilment of the enabling conditions.)
* **Ensure that any infrastructure or other investments funded or co-funded by the EU** require compliance with EU law, specifically the UNCRPD and the EU Fundamental Rights Charter.

## Ensure that monitoring of EU funds involves civil society and national human rights institutions

Monitoring and evaluation of projects funded by the EU are crucial to ensure compliance with the applicable laws, including the UNCRPD and the Fundamental Rights Charter. Monitoring Committees play a key role in this process, but their membership structure and working methods do not allow them to identify and stop investments involving fundamental rights violations.

Involvement of persons with disabilities and their representative organisations in the Monitoring Committees is unsatisfactory. ENIL members have reported that very few have the capacity to be involved in the Committees, or when they have capacity, are not invited to join. Even when organisations of persons with disabilities are part of the Monitoring Committees, they find that they receive insufficient information regarding the investments, and their expertise is not taken sufficiently into account.

The European Commission has additional tools at hand in cases of misuse of EU funds, such as the suspension of payments or the infringement procedure. To this date, the European Commission has not launched an infringement procedure on the basis of investments that violate the rights of persons with disabilities (including investments in institutions and other segregated settings, the lack of accessibility or the lack of involvement of persons with disabilities and their organisations), despite numerous complaints from ENIL in this regard. On the contrary, in response to our complaints, the Commission has argued that no action can be taken due to the shared management principle.

In examining ENIL’s complaints, the Commission has given priority to the self- assessment of the Managing Authorities (on whether they violate the relevant laws, including the UNCRPD and the Fundamental Rights Charter) and has dismissed evidence by independent human rights institutions and organisations of persons with disabilities.

The challenge of persons with disabilities accessing justice is also demonstrated by the case[[20]](#footnote-20) which ENIL, the Centre for Independent Living Sofia and the Validity Foundation took to the General Court in Luxembourg in 2019, challenging the use of EU funds for building institutions in Bulgaria. The Court found that ENIL and others had no standing, as the claimants should be the those directly affected. This is despite the fact that many of the people directly affected have been deprived of legal capacity and therefore cannot bring a claim themselves to a court of law.

**Recommendations for the next MFF:**

* **Make effective use of all existing sanctions**, including the suspension of payments and the infringement procedure, in cases fundamental rights violations or concerns within projects funded by the EU.
* **Strengthen the current complaints system**, so that an independent investigation is carried out, involving civil society organisations and national human rights institutions (NHRIs). Make sure that an effective response is provided before the funds are effectively spent.
* **Raise awareness within the Managing Authorities and the Commission** of the CRPD Committee’s Guidelines on deinstitutionalisation, including in emergencies and the Commission’s Guidance on independent living, specifically the Checklist in the Annex.
* **Retain the partnership principle in the next MFF**. Include a reference to the Code of Conduct on Partnership in the upcoming regulations and strengthen it to improve involvement of civil society at all stages of EU funds implementation (programming, implementation, monitoring and evaluation).
* **Support Member States in providing reparations to persons with disabilities who are survivors of institutionalisation**, including those that were placed in EU-funded institutions, through the provision of technical assistance and the allocation of EU funding towards reparation mechanisms.
* **Ensure access to justice for people under guardianship** affected by projects funded by the EU. Modify existing legislation to ensure the possibility of third party representation, including by non governmental organisations, at the European Court of Justice.

## Ensure that the EU’s external action supports community-based services that enable independent living

There is no specific strategy on disability inclusion for the EU’s development and humanitarian aid and neighbourhood funding. The EU Strategy on the Rights of Persons with Disabilities 2021-2030 includes a section on international cooperation, with five specific initiatives, but these aim to strengthen existing actions instead of creating new objectives and goals. Furthermore, the actions lack defined timeframes, allocated budget and indicators. As the largest donor of Official Development Assistance globally, this is not sufficient to guide disability-inclusive development aid. Persons with disabilities, organisations of persons with disabilities (DPOs) and Centers for Independent Living globally struggle to access external EU funding, due to the size of the calls, the favouring of pre-approved partners (large organisations and charities), and the difficulty to access funding as small organisations.

In the European Union Guidance Note on "Leaving no one behind - Disability Inclusion in EU External Action”[[21]](#footnote-21), which guides EU’s staff and partners working in external action, the EU recognises the need for its staff and delegations around the world to further work on the implementation of the UNCRPD. The EU has further committed to use of the Organisation for Economic Cooperation and Development’s Development Assistance Committee (OECD-DAC) disability marker to screen 100% of its Official Development Assistance.

In addition, the main financing instrument for international development in 2021 - 2027, the Neighbourhood, Development and International Cooperation Instrument - Global Europe (NDICI)[[22]](#footnote-22), lacks specific goals to advance the UNCRPD, only mentioning persons with disabilities along other marginalised groups. Currently, none of the existing plans, strategies and programmes prioritise the right to independent living and being included in the community.

Progress on advancing independent living through external action seems limited. In ENIL and EDF’s joint 2022 report on the role of the EU in promoting independent living outside the EU[[23]](#footnote-23), we found that, despite the lack of transparency, there are very few projects financed by the EU on deinstitutionalisation, but there are still investments into institutions and small group homes. Deinstitutionalisation is not a funding priority for the EU.

When assessing progress in implementing the UNCRPD in the EU neighbourhood, we are concerned that deinstitutionalisation is not included as a priority, and where deinstitutionalisation projects are being implemented, these are often not in line with the Convention. For example, settings such as small group homes and family-based homes for children have been considered a form of deinstitutionalisation. The 2021 progress report by the Commission on North Macedonia stated: “The deinstitutionalisation process is completed, the remaining four children in institutional care are in transitional period and soon to be resettled. The conditions for children settled into community-based care homes are generally satisfactory.”

Our report also raised concerns about the expertise of those receiving grants to implement deinstitutionalisation. According to DPOs, many projects are focused on research, analyses and development of “individual plans” of residents of institutions, failing to produce any concrete results, with regard to providing opportunities for persons with disabilities to live independently in the community.

Persons with disabilities and survivors of institutionalisation have not been involved as equal partners in the funding cycle (planning, implementation and monitoring). Even where engaged at some stage, they have not been able to make decisions or take a leadership role.

**Recommendations for the next MFF:**

* **Plan a disability inclusion strategy or plan for the upcoming budgetary period**, detailing objectives and goals, with specific timeframes and indicators. Develop this strategy in close consultation with DPOs from the EU and outside the EU.
* **Ensure there is dedicated funding for the development of community-based services that enable independent living of persons with disabilities**, such as personal assistance, and for making mainstream services accessible. Refer to the UNCRPD, its General Comments, the CRPD Committee’s Guidelines on deinstitutionalisations and the Commission’s Guidance on independent living when putting together a list of measures that should be funded.
* **Include safeguards into the fund specific regulations and any accompanying documents or strategies for the EU’s external action**, in order to prevent investments in segregated settings for persons with disabilities. Such safeguards can include a prohibition of investing in institutions, clear definitions based on the UNCRPD and the use of sanctions. Involve persons with disabilities through the whole programming cycles, as equal partners in the process.

## Improve transparency and prohibit investments in institutions under the Recovery and Resilience Facility

As a temporary instrument to help the Member States recover after the COVID-19 pandemic, the Recovery and Resilience Facility (RRF) came with simplified rules and procedures, giving Member States the freedom to use the funds faster and without much scrutiny. Unlike the Cohesion Policy instruments, the RRF regulation did not include any conditions linked to the UNCRPD or the EU Charter on Fundamental Rights.

This has led to the European Ombudsman’s strategic initiative looking into transparency in the implementation and accountability mechanisms in the context of RFF, finalised in September 2023[[24]](#footnote-24). In its decision, the Ombudsman set out a number of recommendations, including that:

“Member States in cooperation with the Commission could improve the ability of stakeholders to monitor the impact of projects and to protect the financial interests of the EU.”[[25]](#footnote-25)

The European Court of Audits has also raised the alarm about the lack of transparency in the investments.[[26]](#footnote-26)

Despite this lack of transparency and the difficulties in monitoring how RRF is used, ENIL has recorded investments into segregated settings for persons with disabilities, in violation of the UNCRPD. For example, an investment of almost 16 million Euros was approved for the building of 15 institutions and day-care centers for persons with disabilities and older people in the Spanish region of Malaga.[[27]](#footnote-27) In Bulgaria, RRF is being used to fund 250 new long-term care facilities - 125 for residential care and 125 for day care, for persons with disabilities; the renovation of 82 existing facilities for residential care for older people; energy efficiency renovations of 840 facilities for social services. This has been described as “modernisation of long-term care” by the European Commission.[[28]](#footnote-28) In Croatia, 8 new institutions for older people will be funded through RRF, with an amount of 49 mil Euros.[[29]](#footnote-29)

**Recommendations for the next MFF:**

* **Based on lessons learnt from the Recovery and Resilience Facility, ensure that the next MFF includes concrete safeguards to ensure compliance of investments with the UNCRPD and the EU Charter of Fundamental Rights.** This includes enabling conditions, transparency requirements and an adequate monitoring system, as well as the partnership principle.
* **Implement fully the recommendations of the European Ombudsman and the European Court of Audits** and ensure that these are taken into account for all funding instruments in the next MFF.
* **Carry out an independent review of the spending under RRF to understand the extent of fundamental rights violations**, involving civil society, including persons with disabilities and their representative organisations.
* **Promote and finance mechanisms to provide reparations to those individual s and groups whose human rights have been violated with RRF investments.** Use the lessons learned to avoid this repeating in the future.

**Annex: Glossary the key terms**

**Independent Living**

ENIL defines independent living as 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 real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and other community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.

See also the definition of Independent Living in the General Comment 5, para 16a.

**Deinstitutionalisation**

ENIL defines deinstitutionalisation as a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. It includes an end to substitute decision-making, including guardianship, and to forced treatment (including in the community). Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become, or to resume being a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation 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.

**Institution**

According to the General Comment 5 and the CRPD Guidelines on Deinstitutionalisation, including in Emergencies, there are certain defining elements of an institution:

* Obligatory sharing of assistants with others
* No or limited influence as to who provides the assistance;
* Isolation and segregation from independent life in the community;
* Lack of control over day-to-day decisions;
* Lack of choice for the individuals concerned over with whom they live;
* Rigidity of routine irrespective of personal will and preferences;
* identical activities in the same place for a group of individuals under a certain authority;
* A paternalistic approach in service provision;
* Supervision of living arrangements;
* A disproportionate number of persons with disabilities in the same environment.
* Provision of housing and support in one package by the same service provider (CRPD 2022, para 16).

By its very definition, Independent Living is impossible in residential settings (CRPD 2017, para 16c).

When it comes to children, anything other than a family (including married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, kafalah, sibling care, extended family, and substitute families or foster care), must be considered an institution. “Family-like” institutions are still institutions and are no substitute for care by a family (CRPD 2017, para 16c).

**Personal Assistance**

ENIL defines Personal Assistance as a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance 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. Personal assistance 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.

See also the definition of Personal Assistance in the General Comment 5, para 16d.

**Disabled People’s Organisation (DPO)**

A Disabled People’s Organisation (DPO) is an organisation led, directed and governed by disabled people, often advocating for disability rights as their main objective. For ENIL, a DPO’s board must be composed of at least 51% disabled people. Self-representation is a key element of a DPO, with disabled people speaking and advocating for themselves, instead of relatives or service providers.

**Center for Independent Living (CIL)**

A Centre for Independent Living (CIL) is a cross-disability organisation controlled by disabled people with a mission to promote social inclusion and mainstreaming of disabilities in all public policies. CILs should focus on personal assistance, peer support and building inclusive communities, information and training activities for both disabled and non-disabled people, policy research from the perspective of the UN CRPD and legal representation for disabled people who want to live independently but have no opportunities to do so.

**Transinstitutionalisation**

Transinstitutionalisation refers to the transfer of residents from a large institution into a smaller institution, often called small group homes. Transinstitutionalisation can be wrongly labelled as a deinstitutionalisation strategy; however, it perpetuates institutional culture and cannot be considered an appropriate form of deinstitutionalisation. The Guidelines on deinstitutionalisation, including in emergencies, label this practice as a violation of article 19 of the UNCRPD.

**Community-based services**

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, healthcare 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, or the need for special transport because mainstream transport is inaccessible, and so on.

**About the European Network on Independent Living**

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination. For more information, see: [www.enil.eu](http://www.enil.eu). Contact person: Rita Crespo Fernandez, rita.crespo-fernandez@enil.eu



Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.

1. ENIL Fact sheet on funding, available from: <https://enil.eu/funding/> [↑](#footnote-ref-1)
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