

Advancing Slowly, Regressing Quickly: First glance at the Right to Independent Living in the European Union Funding of 2021-2027

Briefing by the European Network on Independent Living, December 2023

Introduction

The right to independent living is enshrined in article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).¹ According to General Comment n° 5 of the Committee on the Rights of Persons with Disabilities² and the Guidelines on Deinstitutionalization, including in emergencies,³ parts of the right to independent living are subject to progressive realization, while others require immediate action by governments. Those that require immediate action relate to provisions of non-discrimination, and particularly the obligation to end investments into institutions. Investing into community-based services and support is a matter of progressive realization, and therefore requires timebound strategies and plans. It requires putting all resources available to the achievement of this objective.

Article 26 of the Charter of Fundamental Rights of the European Union (hereafter "the Charter") states that "[t]he Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community." Article 21 of the Charter prohibits discrimination on any ground, including disability.⁴

¹ United Nations Convention on the Rights of Persons with Disabilities, available at <u>United Nations Convention on</u> the Rights of Persons with Disabilities (UNCRPD) | Australian Human Rights Commission

² Committee on the Rights of Persons with Disabilities (2017). General Comment 5 on Article 19 - the right to live independently and be included in the community, available at <u>https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live</u>

³ Committee on the Rights of Persons with Disabilities (2022). Guidelines on deinstitutionalization, including in emergencies, available at https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including

⁴ Charter of Fundamental Rights of the European Union (2012), available at <u>https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A12012P%2FTXT</u>

The European Union's (EU) Multiannual Financial Framework 2021-2027 has a budget of 1.71 trillion euros,⁵ with the potential to strengthen and expand the range of community-based services for disabled people, promote independent living and end discrimination. However, the European Network on Independent Living (ENIL) has consistently recorded investments into institutions and other segregated settings from European Union funds. Despite numerous complaints, these investments have continued, while the investments into community-based and support remain limited. Furthermore, we have been consistently observing a trend of "transinstitutionalization", meaning that disabled people are being transferred from large institutions into smaller group homes, in breach of the UNCRPD.

This briefing is ENIL's first attempt to investigate the planned investments under the multiannual financial framework 2021-2027, focusing on the <u>Cohesion Policy</u> (further: structural funds). This gives us an indication of what future investments we can expect and may serve as a call to action for the European Commission to monitor these funds, and for Member States to redirect this funding for community-based services. This briefing will also highlight good practices, to illustrate how the funds should be spent.

The programming period 2014-2020

During the previous programming period, 2014 to 2020, there were already significant changes introduced into the Common Provisions Regulation (CPR), aiming to prevent investments into institutions. However, ENIL submitted a number of complaints about investments into institutions and other segregated settings, showing that there were insufficient safeguards in the regulations. The European Commission also failed to take the required action to prevent these investments from happening, or sanctioning Member States when the Charter and the UNCRPD were breached.

The Common Provisions Regulation 2014-2020 was the key legislative document for several funding instruments, notably the European Regional Development Fund and the European Social Fund. This regulation included the objective to combat discrimination based on disability, to include accessibility, and added an ex ante conditionality of measures to promote the transition from institutional to community-based services.⁶ This was a thematic conditionality introduced for the first time by the regulation, as a condition that Member States must fulfill to be reimbursed by the European Commission. Therefore, in the twelve Member States where deinstitutionalisation was identified as a thematic priority, they were required to prove

⁵ 2021-2027 long-term EU budget & NextGenerationEU, available at <u>2021-2027 - European Commission</u> (europa.eu)

⁶ Regulation (EU) No 1303/2013 of the European Parliament and of the Council of 17 December 2013 laying down common provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund, the European Agricultural Fund for Rural Development and the European Maritime and Fisheries Fund and laying down general provisions on the European Regional Development Fund, the European Social Fund, the European Social Fund, the European Maritime and Fisheries Fund and laying down general provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund and the European Maritime and Fisheries Fund and repealing Council Regulation (EC) No 1083/2006 (2013), available at <u>EUR-Lex - 32013R1303 - EN - EUR-Lex (europa.eu)</u>

that their national strategic framework included measures related to the transition to living in the community.⁷

The objective of the "transition from institutional to community-based care" was also included in the specific regulations for the key funds previously mentioned - the European Social Fund and the European Regional Development Fund. The European Social Fund's regulation precises that this shall be done "in particular for those who face multiple discriminations".⁸

Despite the regulations clearly promoting deinstitutionalisation, and highlighting the principle of non-discrimination embedded in the Charter and the UNCRPD, there was no clear prohibition to invest into institutions and other segregated settings⁹. During the programming period 2014-2020, ENIL reported examples of investments into segregated settings in several countries and raised concerns about internal Commission guidance which justified such investments.

For instance, funds were allocated to support the building and renovation of institutions using ERDF. Sometimes this was done under the premise of transition to independent living, by building small group homes, day care centres or sheltered workshops, that are also forbidden under the CRPD. Renovations also took place under the wave of energy efficiency efforts, supported by ERDF. Among some examples reported by ENIL, we may find the investment in building a large number of residential care facilities for people with disabilities and older people in Bulgaria, and the building and renovation of institutions for persons with disabilities in Poland, including some with up to 80 or 90 residents.¹⁰

ENIL took multiple actions, including bringing forward complaints to the European Commission, the European Court of Justice, and the EU Ombudsman. Both the European Commission and the European Court of Justice dismissed ENIL's complaints. The EU Ombudsman examined ENIL's complaint and put forward a number of useful recommendations, but this was not followed up by sufficient action from the European Commission.¹¹

Current legal framework for investments

Similar to the previous programming period, the Common Provisions Regulation for the period 2021-2027 includes the thematic enabling condition of the transition from institutional community-based care, in addition to horizontal enabling conditions of

⁷ European Network on Independent Living (2018). Briefing on the Use of EU Funds for Independent Living, available at <u>EU-Funds-Briefing_web0903.pdf (enil.eu)</u>

⁸ Regulation (EU) No 1304/2013 of the European Parliament and of the Council of 17 December 2013 on the European Social Fund and repealing Council Regulation (EC) No 1081/2006 (2013), available at <u>EUR-Lex - 32013R1304 - EN - EUR-Lex (europa.eu)</u>

⁹ Even though this prohibition can be inferred from the EU Charter on Fundamental Rights and the UNCRPD.

¹⁰ ENIL, Funding, available at <u>Funding - ENIL</u>

¹¹ Ibid.

implementation of the UNCRPD and the EU Charter.¹² Unlike 2014 - 2020, the conditions must be met throughout the programming period. At the moment, all EU countries are deemed to be fulfilling these conditions, though there is no public information available on how this conclusion was reached.¹³ The European Social Fund Plus Regulation also includes the objective to promote the transition to community-based living.¹⁴

The European Union's Strategy for the Rights of Persons with Disabilities 2021 - 2030 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".¹⁵

The European Union's Strategy on the Rights of the Child¹⁶ and the Child Guarantee¹⁷ 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 a recognition that these objectives must be sufficiently funded by a range of EU funds.

However, in practice, the European Commission's Legal Services consider that financing an institution can still meet this condition, despite this being clearly laid out as a violation in the legal provisions listed above. The Special Rapporteur on the Rights of Persons with Disabilities Gerard Quinn, during his visit to the EU, confirmed that European Commission's staff responsible for managing funds hold this view.¹⁸ The European Union Ombudsman held a similar view in a 2022 own initiative inquiry,

¹² Regulation (EU) 2021/1060 of the European Parliament and of the Council of 24 June 2021 laying down common provisions on the European Regional Development Fund, the European Social Fund Plus, the Cohesion Fund, the Just Transition Fund and the European Maritime, Fisheries and Aquaculture Fund and financial rules for those and for the Asylum, Migration and Integration Fund, the Internal Security Fund and the Instrument for Financial Support for Border Management and Visa Policy (2021), available at <u>EUR-Lex - 32021R1060 - EN - EUR-Lex (europa.eu)</u>

¹³ We have requested further information about the European Commission's analysis of this enabling condition. We are currently awaiting for the response.

¹⁴ Regulation (EU) 2021/1057 of the European Parliament and of the Council of 24 June 2021 establishing the European Social Fund Plus (ESF+) and repealing Regulation (EU) No 1296/2013, available at <u>EUR-Lex - 32021R1057 - EN - EUR-Lex (europa.eu)</u>

¹⁵ Communication from the Commission to the European Parliament, the Council, the European Economic And Social Committee and the Committee of the Regions. Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030. COM/2021/101 final, available at <u>https://eur-lex.europa.eu/legal-</u> content/EN/TXT/?uri=celex%3A52021DC0101

¹⁶ European Union's Strategy on the Rights of the Child, available at

https://commission.europa.eu/document/download/3f5b8720-5e4e-49a6-9660-795efff97842_en

¹⁷ Council Recommendation establishing a Child Guarantee, available at

https://commission.europa.eu/document/download/51d267dc-1642-4f20-a34f-

⁰²⁰⁰³ea88db8_en?filename=celex_32021h1004_en_txt.pdf

¹⁸ United Nations Special Rapporteur on the Rights of Persons with Disabilities (2022). Visit to the European Union. A/HRC/52/32/Add.1, available at <u>A/HRC/52/32/Add.1</u>: Visit to the European Union - Report of the Special Rapporteur on the rights of persons with disabilities | OHCHR

recommending that the Commission ought to provide Member States and the Commission's staff with unambiguous guidance on implementing article 19 of the CRPD.¹⁹ The European Court of Auditors observed in 2023 a lack of data on projects investing in disabled people, and a generalized weak impact of the EU's policies on disability rights.²⁰

The Recovery and Resilience Facility

Following the COVID-19 crisis and the subsequent impact on economies across the EU, the EU approved a temporary recovery instrument, NextGenerationEU. Its main instrument is the Recovery & Resilience Facility (RRF), providing the monies under grants and loans. The funds are provided according to Member States' National Recovery & Resilience Plans.

Under the RRF, funds are being allocated to support the building and renovation of institutions, including nursing homes for older people. Sometimes, this has been done under the premise of transition to independent living. Similarly to ERDF, RRF has supported the building of segregated settings such as group homes, including under energy efficiency efforts, going against the CRPD. As a concrete example, the government of Catalonia's (Spain) plans to use funds from the RRF for the building of 31 institutions in the region.²¹ In Bulgaria, RRF has been allocated to the building of 250 new long-term care facilities, out of which 125 for residential care and 125 for day care of persons with disabilities. In addition, 82 existing facilities for residential care of older people will be renovated and 820 facilities for social services will undergo energy efficiency renovations.²² The analysis of 12 RRF national plans by the European Expert Group on the Transition from Institutional to Community-based Care has uncovered similar investments, raising concerns about massive increase in institutionalization of persons with disabilities and older people.²³

At the moment, the RRF lacks safeguards to prevent investment in institutions. Existing Guidance and Regulations do not specify any requirements to avoid investing in institutions, and the Guidance to Member States – Recovery and Resilience Facility - Part 1 suggests, under potential investments, the renovation of residential buildings.

¹⁹ European Union Ombudsman (2021). Decision on the own initiative inquiry into how the European Commission monitors EU Structural and Investment funds to ensure they are used to promote the right of persons with disabilities to independent living and inclusion in the community (OI/2/2021/MHZ).

²⁰ European Court of Auditors (2023). Special report 20/2023: Supporting persons with disabilities – Practical impact of EU action is limited, available at <u>Special report 20/2023</u>: Supporting persons with disabilities | European <u>Court of Auditors (europa.eu)</u>

²¹ Information available at Drets Socials atorga 142,3 M€ de Fons Europe... - Govern.cat

²² Information available at <u>https://commission.europa.eu/projects/modernisation-long-term-care_en</u>

²³ Information available at <u>https://deinstitutionalisation.com/2022/03/15/deinstitutionalisation-should-remain-a-priority-for-eu-funding/</u>

In addition, the lack of transparency makes monitoring a challenging task. This has been pointed out by the EU Ombudsman under its strategic inquiry,²⁴ and by the Court of Auditors in their report.²⁵

Operational Programming 2021-2027: Case Study of Portugal

Under the programming period 2021-2027, all countries have in place Operational Programmes (OPs), with the key objectives and investments foreseen for the period. Analysing these documents may be helpful to understand countries' plans and commitments to deinstitutionalisation, to be able to to monitor planned investments into institutions and other segregated settings, and to remind the countries of their own commitments if their investments are not aligned with their OP.

Due to the large number of Operational Programmes, we have focused on the case of Portugal, as a country that has promising plans to support the transition from institutions to community-based support, but also plans for investments into institutions and a lack of safeguards in some cases.

Case Study: Portugal

Portugal manages EU funds at regional level. Therefore, several regions have been analyzed, based on a preliminary analysis that identified regions prioritizing objectives 4A on Qualifications and Employment, and 4B on Health and Social Inclusion. In addition, the national Programme of Demographics, Qualification and Inclusion (PDQI) has also been examined.

Some OPs reference disability inclusion as cross-cutting actions. The PDQI commits to respect the horizontal principles of the Charter, the UNCRPD (including the General Comments), and the EU Strategy on the Rights of Persons with Disabilities. It clarifies that the OP does not support any investments that contribute to segregation or that promote backsliding in the deinstitutionalisation process.²⁶

Under the specific objectives, we find relevant references regarding actions on employment, education, health, social protection, and access to services. Various

²⁴ European Union Ombudsman (2023). The transparency and accountability of the Recovery and Resilience Facility. Case SI/6/2021/PVV

²⁵ European Court of Auditors (2023). Special report 26/2023: The Recovery and Resilience Facility's performance monitoring framework – Measuring implementation progress but not sufficient to capture performance, available at <u>Special report 26/2023</u>: The Recovery and Resilience Facility's performance monitoring framework | European Court of Auditors (europa.eu)

²⁶ Demography, Qualifications and Inclusion Thematic Programme, available at <u>sfc2021-prg-2021pt16cfpr001-</u> <u>10.pdf (portugal2020.pt)</u>

programmes, including Madeira,²⁷ the Norte²⁸ and Centro²⁹ regions, Azores³⁰, and the PDQI, highlight the obligation to comply with the requirements of the UNCRPD, the Charter, and the EU Strategy on the Rights of Persons with Disabilities 2021-2030. Furthermore, these programmes include specific references to the need to promote deinstitutionalization efforts, the building of community-based services, and the obligation to not promote segregation and avoid reversing deinstitutionalization efforts. In particular, Madeira commits to also promote deinstitutionalization efforts for older people, while the PDQI refers to the provision of support for young people in institutions.³¹ In reference to investments into health infrastructure and equipment, Alentejo clarifies that such investments must contribute to the transition from institutional to community-based care.³²

Several programmes reference the pre-existing programme on personal assistance, the Independent Living Support Model (MAVI, *per* its initials in Portuguese), financed by the European Social Fund, as an operation of strategic importance and under several specific objectives. MAVI has been implemented by the Centers of Independent Living in Portugal, and ensuring its continuity could have great impact on the right to independent living. In the PDQI, MAVI is set to be given particular emphasis in monitoring, communication and visibility, even if the financial allocation is not very significant.³³ Lisbon also highlights MAVI, with an envelope of 9.5 million euros, as a key programme which promotes inclusion of disabled people and that reverses trends of institutionalization and family dependence. Lisbon also includes as an activity under the specific objective 4.11 the investment into personal assistance "in support for disabled people or people unable to carry out activities which, due to the limitations arising from their interaction with the conditions of the environment, cannot be carried out on their own" (automatic translation). The target for this investment is to reach 50,000 people by 2024, and 576,000 people by 2029, which is an ambitious commitment.³⁴ In the Algarve region, the promotion of personal assistance is set to have an ultimate objective to "promote a true paradigm shift and a reverse of institutionalization and dependency trends".³⁵

A few programmes refer to the promotion of community-based services. For instance, Azores commits to "strengthen, adapt, requalify and innovate community-based social responses aimed at children, the elderly, people with disabilities or impairments" (automatic translation).³⁶ Along with this commitment, Azores places an emphasis on

²⁷ Madeira Regional Programme 2021-2027, available at <u>Texto_integral_sfc2021-PRG-2021PT16FFPR001-</u> <u>1.2 PRMADEIRA.pdf (portugal2030.pt)</u>

²⁸ Norte Regional Programme 2021-2027, available at <u>sfc2021_pr_norte.pdf (adcoesao.pt)</u>

²⁹ Centro Regional Programme 2021-2027, available at <u>Programa-centro2030.pdf</u>

³⁰ Azores Regional Programme 2021-2027, available at <u>Texto integral sfc2021-PRG-2021PT16FFPR002-</u>

^{2.2}_PRAcores.pdf (portugal2030.pt)

³¹ Madeira Regional Programme 2021-2027, op. cit.

³² Alentejo Regional Programme 2021-2027, available at PR Alentejo.pdf (portugal2030.pt)

³³ Demography, Qualifications and Inclusion Thematic Programme, op. cit.

³⁴ Lisbon Regional Programme 2021-2027, available at sfc2021 pr lisboa.pdf (adcoesao.pt)

³⁵ Algarve Regional Programme 2021-2027, available at <u>20230515_PR Algarve2030_oficial_0.pdf (ccdr-alg.pt)</u>

³⁶ Azores Regional Programme 2021-2027, op. cit.

investments in community-based care to avoid reversing deinstitutionalization efforts and promote the principles of independent living and inclusion, as a safeguard to guarantee that institutions will not be promoted.³⁷ Under objective 4.11, on reinforcing access to quality services, the Norte region allocates EUR 1 million to improve services provided by relatives and in the community,³⁸ while the Centro region includes the promotion of mobile units to improve access to services in the community in low density territories, with a EUR 2 million allocated for this purpose.³⁹

Other positive investments include promotion of accessibility of the environment⁴⁰, investments in inclusive education for disabled learners⁴¹, the reduction of the employment gap,⁴² the empowerment of civil society⁴³, or the improvement of participation of disabled people in society.⁴⁴

Nevertheless, there are aspects in the OPs that may hinder these efforts. In Madeira, despite the clear objectives on inclusion and the commitments to not reverse deinstitutionalization efforts, there is a clause that allows exceptions to this, when negotiated with the European Commission.⁴⁵ As the European Commission's internal legal notes allow for investments in certain cases, we expect that there may be investments approved if demanded, in breach of the UNCRPD and the Charter. Madeira also foresees investments into institutions for older people, clarifying that this have been deemed as compatible with EU environmental regulations, while committing to respect the horizontal enabling conditions to respect the EU Charter on Fundamental Rights and the UNCRPD - despite being in clear breach of these instruments.⁴⁶ In addition, under the PDQI there is a mention of responses for better work-life balance for parents, with an increase in the provision of care services, without ensuring respect to the UNCRPD and leaving the door open to segregated services for disabled children.⁴⁷ There is also a lack of safeguards regarding employment, as while the programming in Lisbon has an objective to reduce the employment gap, there is no guarantee to avoid investments into sheltered workshops or segregated training programmes.48

³⁷ Ibid.

³⁸ Norte Regional Programme 2021-2027, op. cit.

³⁹ Centro Regional Programme 2021-2027, op. cit.

⁴⁰ Demography, Qualifications and Inclusion Thematic Programme, op. cit.

⁴¹ Lisbon Regional Programme 2021-2027, op. cit.; Demography, Qualifications and Inclusion Thematic

Programme, op. cit.

⁴² Lisbon Regional Programme 2021-2027, op. cit.

⁴³ Demography, Qualifications and Inclusion Thematic Programme, op. cit.

⁴⁴ Norte Regional Programme 2021-2027, op. cit.

⁴⁵ Madeira Regional Programme 2021-2027, op. cit.

⁴⁶ Ibid.

⁴⁷ Demography, Qualifications and Inclusion Thematic Programme, op. cit.

⁴⁸ Lisbon Regional Programme 2021-2027, op. cit.

Recommendations

For the European Commission:

- Take action to ensure that investments foreseen into institutions and other segregated settings do not take place.
- When receiving information about unplanned investments into segregated settings, use the available tools to withdraw EU funding, including the use of the infringement procedure.
- Closely monitor those investments that lack sufficient safeguards, and hold Member States accountable to their commitments under the Operational Programmes, where they commit to deinstitutionalization and alignment with the UNCRPD.
- Provide guidance to Member States to promote deinstitutionalization and independent living, in line with UNCRPD *Guidelines on deinstitutionalization, including in emergencies.*
- Identify practices that may be replicated in other Member States and promote them at EU level, ensuring that these practices promote the right to independent living and being included in the community and do not lead to segregation of disabled people.
- Ensure that Disabled People's Organisations (DPOs) are involved in the monitoring of EU funds. In particular, survivors of institutionalization must be consulted in all deinstitutionalization efforts.

For Member States:

- Adopt clear safeguards to end investments into institutions, in line with the UNCRPD and the Charter, and the national deinstitutionalization strategies which are aligned with the UNCRPD and the *Guidelines on deinstitutionalization, including in emergencies.*
- Take steps to involve a diversity of DPOs, including those representing survivors of institutionalization, into monitoring committees and all stages of planning and implementation. Make use of technical assistance funding to ensure they have sufficient capacity to fully participate in these processes, including being able to act as a watchdog.
- Increasingly expand investments into community-based services and support, including personal assistance.

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



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.