



Briefing on the Use of EU Funds for Independent Living

European Network on Independent Living | March 2018



Acknowledgments

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Introduction

This briefing has been prepared by the European Network on Independent Living (ENIL) to highlight action that must be taken if the European Union (EU) is to achieve its objective of facilitating disabled people's transition from institutional care to independent living¹ through the investment of the European Structural and Investment Funds (ESI Funds). It forms part of ENIL's *EU Funds For Our Rights Campaign*², which was launched in November 2016 and aims to encourage the European Commission and Member States to improve the monitoring and complaints system for ESI Funds. In doing so, ENIL and its partners seek to ensure that ESI Funds are used to support the right of disabled people³ to live independently in the community and to prevent such funds from being used to renovate or build new institutions for disabled people, regardless of their size.

The purpose of this briefing is to assist the range of agencies involved in the planning, implementation, monitoring and evaluation of ESI Funds and those whose work focuses on the promotion of the rights of disabled people. As such, it will be of interest to the Managing Authorities and Monitoring Committees of EU Member States, the members of the EU Framework for the UN Convention on the Rights of Persons with Disabilities (CRPD), namely the European Parliament, the European Ombudsman, the European Commission, the EU Agency for Fundamental Rights (FRA) and the European Disability Forum (EDF), as well as disabled people's organisations (DPOs) and civil society organisations (CSOs).

In 2017, as part of the *EU Funds For Our Rights Campaign*, ENIL organised regional meetings with CSOs from 18 EU Member States, to build their capacity to monitor ESI Funds and to understand what progress has been made in facilitating deinstitutionalisation of disabled people. We have also met with a number of country desk officers at the European Commission (from DG Employment, Social Affairs and Inclusion and DG Regional and Urban Policy), as well as Members of the European Parliament (MEPs), to discuss ongoing concerns across the EU.

Drawing from information provided to ENIL by DPOs and CSOs, in particular those who attended the 2017 regional meetings⁴, this briefing identifies key areas of concern and makes recommendations on how such problems might be addressed. Such action is needed given that the institutionalisation of disabled people is still prevalent in the EU. This is demonstrated by the recently published findings of two projects:

- **FRA's project on the right to independent living in the EU (2017):** both the summary report, and the country studies, provide an overview of the types and characteristics of institutions and community-based services in the Member States.⁵
- **Mental Health Europe's "Mapping and Understanding Exclusion in Europe" (2017):** this report maps mental health systems and provides data on the situation of people with mental health problems, including those in institutional care⁶.

Both studies highlight the slow progress towards independent and community living in the EU and the fact that tens of thousands of disabled people remain in institutional care.

1 For definitions of these and other terms, please see Annex C.

2 For more information about the campaign, please see: <http://enil.eu/campaigns/eu-funds-for-our-rights/>

3 The report uses the term 'disabled people', rather than 'persons with disabilities' or 'people with disabilities', to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability.

4 The list of DPOs and CSOs that attended the regional meetings is provided in Annex B.

5 See: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/country-data>

6 See: <https://mhe-sme.org/wp-content/uploads/2018/01/Mapping-and-Understanding-Exclusion-in-Europe.pdf>

Furthermore, a series of reports have highlighted significant concerns about the use of ESI Funds during the current programming period (2014 – 2020), in relation to the ‘transition from institutional care to community living’ of children, disabled people and other user groups⁷. Similar concerns have been raised by the CRPD Committee in its Concluding Observations in respect of a number of EU Member States,⁸ as well as by the Council of Europe Commissioner for Human Rights in this country reports.⁹

Accordingly, this briefing sets out a summary of the key areas of concern in relation to the use of ESI Funds, together with recommendations on what action is needed to address them. It is timely, considering that we are at a mid-way stage for the current programming period (2014 – 2020) and that discussions on the future of EU funding post 2020 are underway. It is also worth noting that, while every effort has been made to verify information included in this briefing, further research is required, in order to have a full picture of ESI Funds implementation across the EU.

Structure of the briefing

- Part 1:** The first part of the briefing sets out the main areas requiring action by the European Commission and the Member States.
- Annex A:** A table with country-by-country information provided to ENIL by organisations participating in the *EU Funds for Our Rights Campaign* regional meetings.
- Annex B:** Contains a list of organisations that have taken part in the Campaign.
- Annex C:** Includes definitions of the key terms used in the briefing.

⁷ See, for example, Community Living for Europe (2017) *Opening up Communities, Closing down Institutions: Harnessing the European Structural and Investment Funds*, at: https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw_opening-up-communities-november-2017_final.pdf, Eurochild (2017) *Facts and Figures: 2017*, available at: <http://www.openingdoors.eu/resources/facts-and-figures-2017/>, European Parliament (2016) *European Structural and Investment Funds and People with Disabilities in the European Union*, available at: http://enil.eu/wp-content/uploads/2016/06/COMMITTEES_PETI_2016_11-09_Study-EUFunds-Disabilities.pdf, ENIL (2016) *Working Together to Close the Gap Between Rights and Reality*, available at: <http://enil.eu/wp-content/uploads/2016/06/Working-Together-to-Close-the-Gap.pdf>, Eurochild (2015) *Opening Doors for Europe's Children*, available at: <http://www.openingdoors.eu/wp-content/uploads/2015/03/Opening-Doors-Es-if-Report-lowres-.pdf>, Open Society Foundations (2015) *The Role of the EU in Promoting and Protecting the Right of People with Disabilities to Live in the Community*, available at: <https://www.opensocietyfoundations.org/sites/default/files/community-not-confinement-20151014.pdf>

⁸ European Parliament (2016) *European Structural and Investment Funds and People with Disabilities in the European Union*, p. 33. See: http://enil.eu/wp-content/uploads/2016/06/COMMITTEES_PETI_2016_11-09_Study-EUFunds-Disabilities.pdf

⁹ *Ibid*, p. 24.

Areas Requiring Action

ENIL's concerns and recommendations for remedial action are considered under the following headings:

1. Failure to comply with the thematic *ex ante* conditionality on deinstitutionalisation
2. Investments that perpetuate the segregation and isolation of disabled people
3. Inadequate monitoring and complaints procedures
4. More attention needed to evaluate ESI Funds' impact on Independent Living
5. Barriers to achieving meaningful participation and lack of information about the use of ESI Funds
6. Continued investment of national funds into institutional care

1. Failure to comply with the thematic *ex ante* conditionality on deinstitutionalisation

Concern: To date, there is slow progress in some Member States in establishing strategies that reflect a clear commitment to attaining the goal of independent living.

As ENIL highlighted in its 2016 report on the use of ESI Funds, there is lack of 'strategic vision for the transition from institutional care to community living'. We explained that:



"Despite the crucial importance of developing strategies for the transition from institutional care to community living, not all Member States have such strategies in place. In most of the [Operational Programmes] considered, the measures for the transition from institutional care to community-based services are not framed within the context of a strategic vision for community living."¹⁰

Similarly, a 2016 study for the PETI Committee at the European Parliament identified problems with the planning and implementation of deinstitutionalisation processes, and inadequate development of accessible community-based services, as the main reason for the failure to provide more disabled people with the right to independent living in the previous programming period (2007 – 2013).¹¹

The lack of strategic vision on community living is at odds with the thematic conditionality related to "Promoting social inclusion, combating poverty and any discrimination", which requires a number of Member States to have in place a national strategy for poverty reduction that "includes measures for the shift from institutional to community-based care" (also referred to as 'deinstitutionalisation strategy').¹²

¹⁰ ENIL (2016) *Working Together to Close the Gap Between Rights and Reality*, p. 35.

¹¹ European Parliament (2016) *European Structural and Investment Funds and People with Disabilities in the European Union*, p. 26 – 28.

¹² Common Provisions Regulation, Annex XI. This relates to twelve Member States for which the Commission has established an "identified need" for deinstitutionalization: Bulgaria, Czech Republic, Estonia, Greece, Hungary, Lithuania, Latvia, Poland, Romania, Slovenia, Slovakia and Croatia.

Moreover, the absence of a comprehensive deinstitutionalisation strategy goes against the CRPD. As parties to the CRPD, both the EU and Member States¹³ are required to take action to ensure that disabled people can live in the community as equal citizens (in other words, enjoy their right to living independently in the community). In this regard, the views of the Committee responsible for overseeing the progress made by governments in implementing the CRPD (the CRPD Committee) are significant. Its 2017 General Comment No. 5 on Article 19 CRPD (living independently and being included in the community)¹⁴ provides detailed guidance on States Parties' obligations under this article.

The CRPD Committee emphasises the need for a strategic approach to address the institutionalisation of disabled people:



“...policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family.”

In the CRPD Committee's view, “States parties must adopt a strategy and a concrete plan of action for de-institutionalization” which includes “the duty to implement structural reforms, to improve accessibility for persons with disabilities within the community and raising awareness among all persons in society about inclusion of persons with disabilities within the community”.¹⁵

Notwithstanding such a requirement, some Member States have failed to put in place comprehensive strategies for deinstitutionalisation. Whereas the CRPD Committee has criticised a number of Member States either because their deinstitutionalisation strategies are inadequate or non-existent,¹⁶ Member States have been able to start using ESI Funds without having such strategies in place.

ENIL is concerned that the lack of concrete plans of action for deinstitutionalisation has resulted in calls for proposals and plans which not only do not facilitate the right to live independently in the community, as set out in Article 19 CRPD and the CRPD Committee's General Comment No 5, but impede the move towards independent living. Such concerns are illustrated by information ENIL has received from the following countries:

Bulgaria: Rather than being about facilitating disabled people's access to independent living, the process of deinstitutionalisation has been described as “deceptive”, in that it consists of moving “large cohorts of people from large residential facilities to small group homes with no significant difference in the provision of care”. Other points raised include concerns about the adequacy of legislation for the provision of community-based services, the absence of any public discussion about the process of deinstitutionalisation with regard to children and young people, and the general lack of vision of independent living.¹⁷

Croatia: The current deinstitutionalisation strategy, which has resulted in a number of disabled people leaving institutions and moving into community, has not led to a change in by-laws that regulate how services are provided. As a result, disabled people that have moved into community settings have to

13 Ireland is the only EU Member State that has not ratified the CRPD, though ratification has been announced for March this year.

14 General comment No. 5 (2017) on living independently and being included in the community, available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3Kjj-eH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh>

15 *Ibid*, para 57.

16 European Parliament (2016) *European Structural and Investment Funds and People with Disabilities in the European Union*, p. 28.

17 Kukova, Slavka (2017) Country report on the European Semester 2016/2017 (Academic Network of Disability Experts).

abide by the same rules as those living in institutions (for example, they may not be allowed to have keys to their apartment, or they may have to ask for permission each time they want to go out). This shows that the balance of power between the user and the service provider has not changed in the process of deinstitutionalisation. Thus, service users are not able to change the provider if they are not happy with the service they receive, and there is no pressure on the service providers to constantly improve and personalise their service, based on the users' needs and requirements. Once disabled people are placed in a particular community setting, they have no option of leaving the place.

Hungary: The lack of strategic vision has resulted in plans to move 2,500 disabled people into smaller institutions, without eliminating institutional culture. There are no plans for closing down large residential institutions, most of which will be converted into 'service centres', or developing personalised support, such as personal assistance and other community-based services. In addition, the strategy for deinstitutionalisation – which lacks a concrete action plan, with deadlines and responsible actors – covers only the so-called 'nursing/caring institutions', and institutions with more than 50 residents.

Lithuania: The lack of coordination between municipalities in relation to deinstitutionalisation has negatively affected the calls for tenders for the development of community-based services.

Slovakia: The lack of coordination between the allocation of ESI Funds – the European Social Fund (ESF) and the European Regional Development Fund (ERDF) – is due to the fact that the two Managing Authorities (i.e. two Ministries) do not share the same vision.

Some Member States, such as **Greece** or **Slovakia**, have no plans for deinstitutionalisation in place or they do not guarantee that all public investment (i.e. both ESI Funds and the state funds) will go towards the development of community-based services.

ENIL has also received reports of delays in the launching of calls for proposals that aim to support the process of deinstitutionalisation in some Member States (for example, **Slovakia**, **Croatia**, **Czech Republic**, **Slovenia** and **Romania**). Although 'transition from institutional care to community living' is a complex process, any delays mean prolonged stay in institutions for those concerned and less time to develop and put in place quality community-based services.

For example, in **Slovenia**, the planning had started three years ago, but to date, no calls for proposals in support of deinstitutionalisation have been launched. In **Croatia**, the lack of coordination between different Ministries, in relation to funding and state property (which is used to house those leaving institutions), has been cited as the main reason for delays. As a result, more than 6,000 disabled people in institutional care are facing continued violations of their CRPD rights.

Recommendation 1: Provide training on the General Comment on Article 19

To increase awareness of the CRPD generally and Article 19 in particular, and their relevance to the use of ESI Funds to facilitate the transition from institutional care to independent living, ENIL recommends that:

- The European Commission and Managing Authorities **organise training on the General comment No 5 on Article 19 CRPD** for the officials responsible for the relevant Operational Programmes, as well as for those involved in the planning, monitoring and evaluation of the relevant OPs. With regard to the European Commission, it is important that officials of all Directorate Generals (DGs) that deal with investments relating to disabled people take part in such training.

- The European Commission and Managing Authorities ensure that such **training is developed and delivered by organisations promoting the right to live independently in the community**, and that it includes lived experiences of disabled people in institutional care and the community.

Recommendation 2: Ensure compliance with the CRPD

To ensure that the projects supported by ESI Funds comply with the CRPD, ENIL recommends that:

- The European Commission should consider how to incorporate the **guidance of the General Comment on Article 19** (for example, by developing indicators) in its work to monitor the use of ESI Funds and evaluate the extent to which projects facilitate progress towards independent living.

Recommendation 3: Review *ex ante* conditionalities for EU Funding post 2020

As the CRPD Committee has made clear, a comprehensive strategy for implementing the shift from institutional care to independent living is essential. For this reason, ENIL recommends that:

- The European Commission takes steps to ensure that for the post 2020 financing period, **the *ex ante* conditionalities require that comprehensive strategies are in place**. Whether these are referred to as ‘deinstitutionalisation strategies’ or strategies for independent living is less important than the content of such strategies, which must set out the process to be undertaken by the Member State to facilitate the move from institutional care to living independently in the community, in compliance with the CRPD.
- **The European Commission develops a means of evaluating the strategies** that takes into account the CRPD, in particular Article 19 and any relevant recommendations by UN treaty bodies and other human rights mechanisms. It will also be necessary to ensure that DPOs and CSOs are consulted in the evaluation of Member States’ strategies.

2. Investments that perpetuate the segregation and isolation of disabled people

Concern: ESI Funds continue to support projects that exclude disabled people from community life, rather than promote their social inclusion.

As a result of ENIL’s advocacy activities, there is increased awareness about the fact that investment into ‘care villages’ and other forms of ‘transinstitutionalisation’ are not in compliance with the ESI Funds Regulations. It was also announced that the European Commission would ensure that funding aimed at increasing energy efficiency, for example, is not used as an excuse to renovate institutions for disabled people or other groups.¹⁸ In addition, as part of the European Expert Group on the Transition from Institutional to Community-based Care (EEG), we have successfully advocated for the revision of a call for proposals in the Czech Republic, which could have resulted in new institutions being built. ENIL welcomes these developments, but is concerned that there are a number of other cases, where neither the European Commission nor the Managing Authorities have taken action to ensure compliance with the UN Convention on the Rights of Persons with Disabilities, the Charter on Fundamental Rights and other EU laws and policies.

¹⁸ This statement was made by Andor Urmos, from DG Regional Policy, during the 11th European Forum on the rights of the child: Children deprived of their liberty and alternatives to detention (7 – 8 November 2017).

Evidence collected by ENIL highlights the inappropriate use of ESI Funds in a number of countries. We have received numerous reports of plans to replace large residential institutions with small group homes and similar residential facilities, as well as with foster care for disabled adults. While these services may be located in the community, they perpetuate the segregation and social exclusion of disabled people by failing to provide disabled people with the opportunity “to choose their place of residence and where and with whom they live on an equal basis with others”¹⁹. ENIL is also concerned that Member States are not using ESI Funds to invest in mainstream services, such as housing, employment or inclusive education.

In relation to living arrangements, the General Comment on Article 19 CRPD states:



“Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment...”²⁰

The following examples from specific countries illustrate the range of concerns about the inappropriate use of ESI Funds:

Bulgaria: So-called Family-type Accommodation Centres (FTACs) are being established, as well as protected and monitored housing²¹, all of which are defined as ‘facilities for community based services’. Although often referred to as an example of successful use of ESI Funds for deinstitutionalisation²², the Centre for Independent Living Sofia and the Bulgarian Helsinki Committee have questioned whether Bulgaria’s use of ESI Funds complies with the CRPD. Both organisations have highlighted numerous human rights violations in small group homes and similar residential facilities, notably in FTACs, some of which were funded by ESI Funds²³.

FTACs are residential community-based services, where the daily life of a disabled person is not much different than in an institution. Disabled people are often placed in such centres by their guardian, not based on their own choice, and may have no say in what activities they take part in during the day²⁴. There is evidence of the fact that the care/support provided is of institutional type; moreover, there are no quality standards in place to ensure compliance with Article 19 CRPD, no change in the way the service is funded (with funds going to the centre, rather than the user), and no plans for residents to live independently in the future.

19 UN Convention on the Rights of Persons with Disabilities, Article 19, available at : <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19>

20 General comment No. 5 (2017) on living independently and being included in the community, para 16(c).

21 Family-Type Accommodation Centres (FTAC), protected and monitored housing refer to different types of residential settings for disabled people.

22 See, for example, Community Living for Europe (2017) *Opening up Communities, Closing down Institutions: Harnessing the European Structural and Investment Funds*.

23 See: [http://www.bghelsinki.org/media/uploads/documents/reports/special/2016_nesluchvashtata_se_deinstitucionalizacia_na_licata_s_umstveni_zatrudnenia_v_bulgaria_\[978-954-9738-37-7\].pdf](http://www.bghelsinki.org/media/uploads/documents/reports/special/2016_nesluchvashtata_se_deinstitucionalizacia_na_licata_s_umstveni_zatrudnenia_v_bulgaria_[978-954-9738-37-7].pdf) and <http://www.cil.bg/userfiles/nabliudatelnitza/Report-DI-Final.pdf>

24 Kukova, Slavka (2017) Country report on the European Semester 2016/2017 (Academic Network of Disability Experts).

Croatia: The Ministry for Demography, Family, Youth and Social Policy continues to place disabled adults into foster homes and is drafting a new law that will result in an even greater number of adults being fostered, as part of the process of deinstitutionalisation. Placement of disabled adults into foster families is funded by the ESF, as a community-based service, despite recommendations by the CRPD Committee²⁵ and reports by the Croatian Ombudsperson for Persons with Disabilities and the Human Rights Watch²⁶, which found this practice to be in violation of disabled people's human rights.

Greece: There has been limited progress towards deinstitutionalisation and services for disabled people are still, by and large, provided in large institutions. There are concerns that the plans for reforming institutions in Attica and the Western Greece (including the institution in Lechaina, which has received international attention due to disabled children found locked in cages²⁷) will result in moving residents into smaller institutions, without proper planning and preparation, and no opportunity for them to have a say in the process, or a chance to decide where and with whom they would like to live.

Hungary: ENIL, together with other human rights organisations, has raised concerns about the Hungarian government's 'deinstitutionalisation' plans, which are financed with ESI Funds²⁸. Such plans include the development of new living facilities ('group homes') in remote, often inaccessible and otherwise inadequate locations, continued reliance on day care centres (some of which are located in the old institutions), denial of the right to choose where and with whom to live, the lack of personalised support, failure to involve residents in decisions about their move, failure to provide opportunities for participation in community life, and the lack of plans to close the large institutions. The plans, approved by the Managing Authority, do not even foresee supported decision-making for those involved in the process. Thus, disabled people will move into new homes, but will have no more say over their daily lives than when they lived in the large institutions.

Romania: ENIL has written to the Romanian Government to raise concerns about the focus on developing protected housing units – i.e. small group homes – and day care centres, as the only alternative to institutional care, in particular for people with intellectual disabilities and people with mental health problems. In ENIL's view, the absence of other housing solutions and person-centred support services, such as personal assistance, as well as a lack of investment into inclusive education and other mainstream services is highly problematic. Similar concerns have also been expressed by the Centre for Legal Resources in its report analysing Romania's plans for the use of ESI Funds under the priority 'transition from institutional to community-based care'²⁹.

Slovenia: Concerns have been raised with ENIL about plans by the Ministry of Social Affairs to build 100 identical housing units for at least 900 people, using ESI Funds. There are no plans detailing how the support will be provided, to enable disabled people's move from institutions into community. Although the Ministry has a deinstitutionalisation policy in place, new institutions are being built and old institutions renovated with funds from the national budget³⁰.

25 CRPD Committee's Concluding Observations on Croatia, 2015, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en

26 See: Pravobraniteljica za osobe s invaliditetom (2017) Postivanje prava osoba s invaliditetom smještenih u udomiteljskim obiteljima i obiteljskim domovima, available at: https://www.posi.hr/index.php?option=com_joomdoc&view=docman&gid=126&task=cat_view&Itemid=189 and Human Rights Watch, Croatia: Locked Up and Neglected, 6 October 2014, available at: <https://www.hrw.org/news/2014/10/06/croatia-locked-and-neglected>

27 See: <https://www.hrw.org/news/2014/11/18/dispatches-greece-no-excuse-caging-children>

28 See: <http://enil.eu/news/hungarian-government-must-suspend-redesign-deinstitutionalisation-projects-affecting-2500-people-disabilities/>

29 Centrul de Resurse Juridice (2017) Report final – Manual instrumente, Clinica Juridica Mobila.

30 See: <http://www.regionalobala.si/novica/center-obala-na-debelem-rticu-raste-bodo-ujeli-napovedano-otvoritev>

Portugal: Smaller institutions are being built, using ESI Funds. There is evidence that the Azores Region is building a 16-person residential home for young people and disabled adults ‘temporarily or permanently prevented from residing in their family environment’. Although, according to the project description, the home aims to promote ‘a qualified occupation that contributes to their well-being, developing strategies for reinforcement of self-esteem and valorisation’, ENIL is concerned that such congregate care will remove disabled people from their family and community, and reduce opportunities for participation, rather than promote their independence.

Moreover, despite the prohibition of using ESI Funds to build or renovate long-stay residential institutions³¹, this practice persists in some Member States.³² In this regard, the CRPD Committee states in its General Comment on Article 19 that one of the core elements of Article 19 is “to use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services”³³.

Thus, for those Member States in which disabled people continue to be institutionalised, it is essential that funding (whether national or ESI Funds) is re-directed from maintaining institutional care to developing community-based alternatives.

Recommendation 4: Action to prevent the inappropriate use of ESI Funds

To prevent ESI Funds supporting projects that perpetuate the social exclusion of disabled people, ENIL recommends that:

- The European Commission **investigates when they are informed of potential ‘misuse’ of ESI Funds and intervenes in all cases where evidence suggests that the projects planned or approved for funding contain elements of institutional culture**, or in other ways segregate or exclude disabled people from the community.
- The European Commission **makes clear to Member States’ Managing Authorities that ESI Funds must not be used to support projects that exclude disabled people from society** and where this is likely, EU funding will be terminated, unless the project is revised or the ESI Funds are redirected to projects for the development of genuine community-based services that facilitate access to independent and community living.
- Managing Authorities **work with organisations promoting independent living**, to ensure that the projects to be funded with ESI Funds comply with Article 19 CRPD.

³¹ European Expert Group on the Transition from Institutional to Community-based Care (2014) *Toolkit on the Use of EU Funds for the Transition from Institutional to Community-based Care*, available at: <http://www.deinstitutionalisationguide.eu/?p=7>

³² See Annex A.

³³ General comment No. 5 (2017) on living independently and being included in the community, Core elements, para h.

3. Inadequate mechanisms for monitoring ESI Funds

Concern: The existing monitoring systems – in the Member States and at the European level – are not robust enough to prevent the use of ESI Funds for projects that perpetuate the social exclusion and segregation of disabled people.

That the monitoring system plays a key role in preventing ESI Funds from being used for the building or renovation of institutions, and for ensuring that quality community-based services are supported instead, has been highlighted by the European Ombudsman³⁴, by the Petitions Committee at the European Parliament³⁵ and, most recently, in the Council Conclusions on community-based care and support for independent living. The Council has invited the European Commission and the Member states to:



“Follow closely the monitoring of the use of ESIF and other relevant EU funding mechanisms to encourage the transition from institutional to community-based care”³⁶

Given the important role of monitoring, action is needed to address the inadequacies of the current system. These have been set out in a number of reports³⁷.

ENIL's report, 'Towards a More Effective Monitoring and Complaints System'³⁸ highlighted a range of areas in which work is needed by the European Commission and the Member States to ensure a more effective monitoring and complaints system for ESI Funds. Key areas of concern, noted by the report, relate to the membership and work of the Monitoring Committees, the Member States' reports to the European Commission, the manner in which ESI Funds programmes are evaluated and audited, and the way complaints are lodged and investigated. In light of these, the report set out the following conclusions and recommendations:

- a. More information is needed from Member States on their use of ESI Funds;
- b. Monitoring Committees have key role but need support to enable them to exercise their functions effectively;
- c. Action is needed to ensure that people with disabilities are involved in monitoring the use of ESI Funds, as required by the partnership principle;
- d. Although Member States are required to establish an effective complaints procedure, there is little clarity on how this obligation is to be met;

34 Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission May 2015. Available at: <http://www.ombudsman.europa.eu/cases/decision.faces/en/59836/html.bookmark>

35 Committee on Petitions Fact-finding visit to Bratislava, *Mission Report and Recommendations*, 22-23 September 2016. Available at: http://www.enil.eu/wp-content/uploads/2012/06/s_2014_2019_plmrep_COMMITTEES_PETI_DV_2016_11-09_mission_report_SK_FFV_final_EN.pdf

36 Council of the European Union, *Enhancing Community-based Support and Care for Independent Living – Council Conclusions*, 7 December 2017, para 18. Available at: <http://data.consilium.europa.eu/doc/document/ST-15563-2017-INIT/en/pdf>

37 For a discussion on the role of ESI Funds and the need for compliance with the UNCRPD, see for example: Open Society Foundations, 2015, *Community, not Confinement The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community* (author Dr. Israel Butler); Office of the High Commissioner for Human Rights (OHCHR), 2012, *Getting a Life – Living Independently and Being Included in the Community and Open Society Foundations (OSF), 2012, The European Union and the Right to Community Living – Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*.

38 ENIL (2017) *ESI Funds and the Transition from Institutional to Community-based Care – Towards a More Effective Monitoring and Complaints System*, p. 32. Available at: http://enil.eu/wp-content/uploads/2017/07/OurRightsCampaign-Briefing_FINAL.pdf

- e. Insufficient information is provided to the general public on the ESI Funds monitoring mechanisms and there is little opportunity for civil society organisations to provide feedback on how projects funded by ESI Funds are being implemented in practice.

Recommendation 5: Improve the monitoring mechanisms for ESI Funds

Given the concerns about the current monitoring of ESI Funds, ENIL recommends that:

- The European Commission and Managing Authorities, as a matter of priority, put in place a **system to improve the way ESI Funds investments are monitored**. ENIL's recommendations on improving the monitoring and complaints system can be used when discussing changes that should be made to the current system.
- Managing Authorities should ensure that information about the projects selected for funding, as well as information about the Monitoring Committees, evaluations and the post 2020 planning process, is available online, including in accessible formats. This is necessary given that an essential requirement for monitoring is **access to relevant information**.
- Managing Authorities should use the remainder of the current programming period to **increase the capacity of DPOs/CSOs to participate in different stages of ESI Funds use**. This can be achieved by allocating technical assistance or other funding for training, networking, dedicated staff and watch-dog activities.

4. More attention needed to evaluate ESI Funds' impact on Independent Living

Concern: Once programmes have been selected for funding, not enough attention is paid to their impact on the final beneficiaries, their quality of life and the degree of their social inclusion and participation in community.

ENIL has been asked repeatedly to identify examples of projects where ESI Funds have been used to facilitate independent living. Throughout the campaign, we have encouraged our members and other CSOs to share any positive examples.

While there are good examples of the involvement of organisations which promote independent living in the relevant Monitoring Committees (for example, in **Latvia** and **Slovakia**), and in the planning process for the next programming period (for example, in **Slovakia**), it is more difficult to identify projects that have facilitated independent living of disabled people.

Partly, this is because many Member States have only just started the process of moving from institutional care to independent living. Some promising projects include using the European Social Fund to support personal assistance (for example, in **Croatia**), although a full evaluation would be needed to establish compliance with Article 19 CRPD. Other projects, which claim to support independent or community living (whether it is about children, people with mental health problems, adults with disabilities or homeless people), would also require a comprehensive evaluation, involving organisations representing disabled people, or those advocating for deinstitutionalisation and independent living.

Recommendation 6: Involve disabled people in the evaluation of the support they receive

ENIL considers that any evaluation of projects funded by the EU must include the views of the people who were intended to benefit from that initiative. ENIL therefore recommends that:

- The European Commission develops a **process for evaluation of projects that are intended to promote independent living** that involves interviews with the individuals who receive the relevant services and support, to ascertain the extent to which the projects have had a positive impact on their lives and have helped them live independently in the community. This evaluation should not just consider individuals' access to community-based support, but also to mainstream services, including housing, transport, education and health care.

5. Barriers to achieving meaningful participation and lack of information about the use of ESI Funds

Concern: Disabled people and their representative organisations are still largely excluded from the process of ESI Funds planning, implementation, monitoring and evaluation. There is little evidence of the use of ESI Funds to facilitate access to the right to independent living.

ENIL is concerned that there are significant barriers that prevent DPOs and other non-governmental organisations from participation in the planning, implementation, monitoring and evaluation of ESI Funds. This is despite the European Code of Conduct on Partnership (ECCP)³⁹, which includes the requirement that disabled people and their representative organisations (DPOs) are involved at all stages of ESI Funds use. Some of the reasons which make participation difficult or impossible are:

Exclusion from the Monitoring Committees: While some organisations which took part in ENIL's regional events are members of the relevant Monitoring Committees, many do not have any information about the work of the Monitoring Committees or how to become a member. This is especially true of grassroots organisations, as opposed to larger, umbrella organisations or those regularly consulted by the Government. Coordination among civil society organisations is also lacking in many countries, thereby making it difficult for the organisations that are members of the Monitoring Committees to share information with other national disability and human rights organisations.

Lack of capacity: The level of knowledge among DPOs about ESI Funds is still very low. ENIL is concerned that DPOs are not being supported sufficiently by the Managing Authorities (support could be provided, for example by utilising funds for technical assistance or civil society development).

Difficulties in accessing information: Although transparency is one of the requirements for ESI Funds use⁴⁰, ENIL is concerned about the barriers imposed by some of the Managing Authorities in relation

39 European Commission's Delegated Regulation (EU) No 240/2014 on the European code of conduct on partnership in the framework of the European Structural and Investment Funds. Available at: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2014.074.01.0001.01.ENG

40 Regulation (EU) 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 Cohesion Fund, the European Agricultural Fund for Rural Development and the European Maritime and Fisheries Fund and repealing Council Regulation (EC) No 1083/2006 ('the CPR'), available at: http://ec.europa.eu/regional_policy/en/information/legislation/regulations/

to information on ESI Funds investments. This makes it more difficult to detect problems, but also to detect good practices. In some Member States, CSOs are denied access to social care or psychiatric institutions, therefore reliable, impartial information about the quality of care and practices in residential facilities is not available. In many Member States, information is not available online or in an accessible format.

The number of obstacles faced by CSOs in some countries is illustrated by the example in **Hungary**. There, for example, information on which projects are to be funded under the Operational Programme covering deinstitutionalisation was not publicly available. To obtain such information, an organisation representing people with intellectual disabilities (ÉFOÉSZ) submitted a freedom of information request to the Directorate-General for Social Affairs and Child Protection (SZGYF). SZGYF refused to release the documentation about the projects selected, forcing ÉFOÉSZ to file complaints against the Government in a civil court and before the National Authority for Data Protection and Freedom of Information. It was only after this that the Government department responsible for the implementation of ESI Funds released the selected applications to ÉFOÉSZ, who made them public in September 2017.

Legal capacity and failure to build on good practice: Many disabled people who live in institutions are under guardianship (i.e. are deemed to lack legal capacity), which means that they are not able to make important decisions, such as where they will live or with whom. Nor are they consulted in the process of ESI Funds implementation, monitoring or evaluation, even if the use of such funds directly affects them. In **Romania**, NGOs that provide community-based services for adults with disabilities have reported to ENIL that they are not informed or consulted about ESI Funds investments. The NGOs are concerned that rather than facilitating deinstitutionalisation, ESI Funds are to support plans to move disabled people from larger into smaller institutions.

Co-financing requirement: In its report for the Petitions Committee at the European Parliament, ENIL has criticised the additional requirements placed on civil society organisations to co-finance the National project for deinstitutionalisation in **Slovakia**. Such an approach is likely to mean that these organisations are not able to participate in the planned activities.⁴¹

Closed calls: The closed nature of the calls, whereby only those pre-selected by the Managing Authorities can apply (for example, large long-stay institutions earmarked for full or partial closure, Government bodies responsible for service provision or the local authorities) can also act as a barrier to NGO participation. In some countries, like **Greece**, in order to apply, NGOs must obtain a written approval from the respective Ministry, which needs to be submitted together with the project documentation. This is of concern, as partnership with NGOs is important to ensure that the projects funded address the needs of different user groups, and build on the good practice developed by NGOs.

Moreover, there is a notable lack of information about the projects that are receiving ESI Funds, which would help DPOs, CSOs and the European Commission establish the extent to which such projects are helping to facilitate disabled people's right to live independently, their social inclusion and participation. Descriptions of the projects tend to focus on the number of residential facilities constructed, the number of people moved, the number of day care services opened, without any discussion of the quality of support provided, the residents' ability to make decisions about their everyday lives, or other elements of Article 19 CRPD.

⁴¹ European Parliament (2017) *European Structural and Investment Funds and People with Disabilities: Focus on the Situation in Slovakia*, p. 13. available at: http://ec.europa.eu/regional_policy/en/information/legislation/regulations/

Recommendation 7: Enhance the implementation of the partnership principle

While welcoming the European Commission's efforts to promote the partnership principle through various initiatives at EU level (such as the Structured dialogue on ESI Funds and the ESF Thematic Networks), it is essential that the barriers to participation noted above are addressed. Accordingly ENIL recommends that:

- The European Commission takes steps to improve its **monitoring of the quality of CSO engagement at the national level**. It is important to understand not only whether the Managing Authorities involve CSOs at all, but to what extent they are able to influence the process of ESI Funds use, how the members of the Monitoring Committees are selected, which organisations are excluded from the process etc. This is especially relevant considering FRA's report on the challenges facing CSOs working on human rights in the EU⁴², which identified the lack of appropriate involvement of civil society in law- and policy-making, difficulties in accessing funding and legal restrictions as some of the factors that undermine the work of CSOs in the EU. Given these increasing challenges facing CSOs, it is important for the European Commission to formulate better guidance and step up monitoring of the European Code of Conduct on Partnership in the next programming period.
- The European Commission and the Managing Authorities should consider **how to involve the most marginalised groups of disabled people**, including people with intellectual disabilities, people with mental health problems, and those in institutional care, in decisions on ESI Funds use. Although this is set out in the ECCP as part of the partnership principle⁴³, it is not being implemented in practice.
- The European Commission should encourage Member States to **publicise information about the projects funded**, including whether and how they facilitate disabled people's access to independent living. It is imperative that there are systems in place for independent monitoring of all residential settings, including by allowing independent CSOs access to institutions.

6. Continued investment of national funds into institutional care

Concern: EU Member States continue placing disabled people into institutional care, by building new state-funded residential care facilities. This is not seen as a 'European problem' despite the fact the European Union and all but one Member State are party to the CRPD, and thus required to provide disabled people with the right to independent living.

ENIL has received reports from CSOs based in **Belgium, France, Germany, the Netherlands, Slovenia and Spain** about the continued investment of national funds into institutional care, as well as the lack of EU support to facilitate independent and community living for disabled people. For example:

Netherlands: The European Social Fund (ESF) is used mostly for employment and labour market reintegration of the long-term unemployed, but this does not include disabled people. At the same time, 60% of disabled people live at home with their parents, without adequate support or employment opportunities, and many of these are likely to end up in institutions.

⁴² EU Fundamental Rights Agency (2017), *Challenges facing civil society organisations working on human rights in the EU*, available at : <http://fra.europa.eu/en/publication/2018/challenges-facing-civil-society-orgs-human-rights-eu>

⁴³ Preamble, para 4, states: "Specific attention should be paid to including groups who may be affected by programmes but who find it difficult to influence them, in particular the most vulnerable and marginalised communities, which are at highest risk of discrimination or social exclusion, in particular persons with disabilities, migrants and Roma people."

Other countries, such as **Germany, France and Belgium**, lack comprehensive deinstitutionalisation strategies and continue to institutionalise high numbers of disabled people (in large institutions, village communities or other types of congregated settings)⁴⁴. ENIL has also noted a lack of knowledge by DPOs in these countries on how ESI Funds can be used to support the transition from institutional care to community living, and a lack of interest by the European Commission in the situation in these countries (due to the fact that none of the services are funded by the EU).

Recommendation 8: Encourage more Member States to use ESI Funds for deinstitutionalisation

Many Member States of the EU have large numbers of disabled people in institutions and a lack of community-based alternatives. As highlighted in the Common European Guidelines on the Transition from Institutional to Community-based Care and the Toolkit on the Use of EU Funds⁴⁵, ESI Funds can help cover some of the transition costs of moving from one system to another, trigger reforms and encourage innovation in the social and health care, as well as other sectors. ENIL therefore recommends that:

- The European Commission, when negotiating the Partnership Agreements and Operational Programmes for the next programming period, should encourage all Member States that have not yet closed their long-stay residential institutions for disabled people **to include ‘transition from institutional to community-based care’ as one of their investment priorities.**

⁴⁴ For more information, please see FRA’s country reports on independent living (2017), available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/country-data>

⁴⁵ See: <https://deinstitutionalisation.com/eeg-publications/>

Conclusion

ENIL believes there is a strong case for the European Commission, the Managing Authorities and other stakeholders to take action to ensure that ESI Funds and other public investment supports independent living, in compliance with Article 19 CRPD. Although, as noted in the Introduction, we have not been able to obtain a full picture of how ESI Funds are used in the Member States, there is a mounting body of evidence collected by different organisations showing that the potential of EU funds to support the transition from institutional care to quality community-based alternatives is not being realised.

The aim of this briefing was to highlight areas where action is needed *now*. In some cases, such as where plans to build more institutions are already underway, there is a level of urgency that should not be underestimated. Failure to act may result in hundreds of people being moved from larger into smaller institutions, where they are likely to spend the rest of their lives.

ENIL is confident that if action is taken to address the concerns identified in this briefing, the second part of this programming period can produce positive results for disabled people across the EU. We look forward to working with the European Commission and the Member States, including by offering our and our members' expertise on how to develop genuine independent living services, in line with Article 19 CRPD.

Annex A:

Country-by-country information

Country	Key concerns raised with ENIL
Belgium	<ul style="list-style-type: none"> • Deinstitutionalisation is not included as a priority for funding in the Operational Programmes, nor is there a deinstitutionalisation strategy in place; • 85% of disabled children are in special schools, which provide the “whole package”⁴⁶; • Sheltered workplaces are used instead of employment in the open labour market; • The situation is especially difficult in Wallonia, where instead of a personal budget, disabled people get 16 hours per month of home care; • Wallonia’s Personal Assistance budgets have been stopped by the new Government; they are currently only available to 400 persons, who will also lose it eventually; • In Flanders, a recent reform introduced the PFB (‘person following budget’), which has changed the way support is funded. The money, which used to go to the institution, now goes to the person directly. However, given that this budget is calculated based on the average cost of collective care and not on each individual’s support needs, it does not allow the person to live in the community, only to receive the slightly more personalized assistance in an institutional setting; • Every disabled person has the right to apply for a PSB (‘personal support budget’), based on their own support needs. However, even if approved, the budget is not a right but a benefit, based on availability. As a consequence, there are long waiting lists (up to 15 years) to get a PSB; • There are waiting lists for institutions and it is very difficult to get support (including from CSOs) for independent living.
Bulgaria	<ul style="list-style-type: none"> • There is a lack of transparency about the “sole beneficiary procedure” (the intermediate body); i.e. under what circumstances can this procedure be used by the Managing Authority; • Independent living terminology is wrongly used to establish “centres for independent living”, even though these centres do not provide independent living services; • Regulations governing group homes lead to these being run like institutions; • There have been reports of numerous cases of violence in small group homes (including in the media), which show a systemic failure to provide high quality care, with support for empowerment and capacity/skills building to leave the institution and live independently in the community; • To ensure that ESI Funds support independent living, it is important to: mainstream disability in all projects (through an indicator on disability); evaluate each project after it is completed (impact assessment report); make sure that EU funding does not replace state funding for services.
Croatia	<ul style="list-style-type: none"> • There are concerns about delays in launching the calls for proposals under the deinstitutionalisation objective;

⁴⁶ See also: <http://www.openingdoors.eu/wp-content/uploads/2018/02/country-fiche-Belgium-2017.pdf>

- There is a lack of coordination between Government departments in relation to the re-allocation of state property (used to house people leaving institutions) and co-financing, in the framework of deinstitutionalisation programmes;
- Adults with disabilities are being placed in foster families, as opposed to given the opportunity to live independently in the community with support;
- Disabled people continue being deprived of legal capacity and placed under guardianship;
- Many organisations representing disabled people are not listened to with regard to the process of deinstitutionalisation, and are completely excluded from the planning process.

Czech Republic

- There is a lack of understanding about deinstitutionalisation and the process would benefit from CSO input;
- The number of people in residential care has increased by 9,000 since 2016, which represents a 15% increase, bringing the total to 69,000 residents – the biggest increase has been recorded in ‘homes with special regime’, which accommodate mainly people with mental health problems, dementia and substance abuse issues; this is followed by ‘sheltered housing’;
- Although the number of residents in large institutions is decreasing, residents are being moved into smaller institutions (group homes), without access to independent living.

Estonia

- Services developed with the ESI Funds are mostly provided by *AS Hoolekandeteenused*, a state owned organisation, established by the Government, which took over all the Soviet-period institutions for disabled people;
- In the 2007 – 2013 programming period, some of the old institutions were closed and replaced with ‘care villages’;
- In the current programming period, approach has changed to an extent, so that there are 10 people in 3 houses (making up a ‘care village’), with a maximum of 30 people in one unit;
- There is a pilot project for people living in apartments (with 43 people with lower support needs living together), however the service model remains the same. People are mostly organised into groups for different activities during the day and a key factor for moving into these apartments is that one has to manage with lesser amount of assistance. For example, a person needs to be able to be without assistance from 8pm until the morning. As a result, individuals with higher support needs do not access these services and have to live in care villages or other types of cluster housing, where they can have assistance during the night as well;
- Making complaints about the use of ESI Funds is difficult, because care villages are a part of the deinstitutionalisation strategy (despite the fact that a 2016 research project on social care reform confirmed that institutional care in Estonia continues in the smaller settings);
- There is a plan for establishing a new type of service in houses where 24 persons with similar needs will live in ‘families’ of 6; the new service will be based on the same model used in the ‘care villages’.

Germany

- Although social inclusion projects are supported with ESI Funds, this does not include deinstitutionalisation; one of the reasons is that regional authorities do not have deinstitutionalisation as a priority;
- Despite ESI Funds going towards employment initiatives, people in institutions and sheltered workshops are excluded from employment programmes.

Greece

- Some services which were previously funded by ESI Funds are in fact institutions, even though they have different names (for example, a centre for people with disabilities);
- There are delays with launching of the calls in the current programming period, when it comes to the priority on deinstitutionalisation; there are also concerns that the decision as to who will get the funding is made even before the calls are launched;
- Before CSOs can apply for funding, they need to obtain approval from the respective department in the Ministry; this allows the Ministry to deny access to some CSOs and brings into question the fairness of the process; it is also difficult for CSOs to access data on ESI Funds and the projects funded;
- There are concerns about the Lechaina institution (for children with disabilities) and the fact that no ESI Funds have been assigned to support its closure (with the process so far supported by the Lumos Foundation), which may mean that the process of moving residents into the community will not be completed. The government has announced a project for reforming this institution with state funding. However, this project consists of moving residents into smaller homes, with the prevailing institutional culture. The same applies to Government's plans to reform residential care services for disabled people in Attica;
- The social inclusion strategy, which was used to fulfil the relevant ex ante conditionality, includes measures for deinstitutionalisation, but continues to rely on residential care. Currently, there is no comprehensive deinstitutionalisation action plan or strategy which includes all public investment and aligns efforts (between the state and ESI Funds), and is based on the principles of the CRPD.

Hungary

- There are concerns about the strategic vision, i.e. the country's approach to deinstitutionalisation – a process reliant solely on ESI Funds;
- There are a number of problems with the projects designated for funding: community-based services for those leaving the institutions are not being established in the capital; those leaving the institutions cannot choose which part of the country they will live in; small group homes are being established in remote, and often inaccessible locations (15 settlements with less than 500 inhabitants); the cost per person (leaving the institution) is very high (9 mil HUF);
- Tenders are only open to social care institutions; deinstitutionalization strategy does not cover everyone currently in institutional care;
- Although deinstitutionalisation strategy requires that large residential institutions are no longer used for residential care, 'service centres' (i.e. day care centres for disabled people) are to be created on the grounds of the existing large institutions;
- NGOs are not allowed to monitor institutions, and there is a lack of meaningful involvement of DPOs and users of institutions in the deinstitutionalisation process;
- Despite some NGOs having access to the Monitoring Committees, they are not an independent monitoring mechanism;
- Overall, there is a negative climate for NGOs in the country, with NGOs being exposed to continued repressive measures and public attacks by the Government.

Latvia

- The only concern reported was that municipalities are worried about deinstitutionalisation, and that the city of Riga has refused to participate in the process.

Lithuania

- Concerns relate to the deinstitutionalisation strategy, launched in 2014, targeting children, children with disabilities and adults with disabilities in institutions – the implementation of which is supported by ESI Funds (50 mil EUR);

- Under this plan, 26 institutions have been chosen for ‘reorganising’, but the implementation plan contains problematic results and indicators (with concerns that residents will be re-institutionalised in smaller institutions);
- Public tenders cover the whole region, but there is a lack of coordination with municipalities; in addition, tenders do not sufficiently include the development of community-based services;
- There are concerns about the lack of independent monitoring of the process; complaints raised in the Monitoring Committees are not taken into consideration;
- In the previous programming period, ESI Funds have been used for renovating institutions, including those now included in the deinstitutionalisation process.

Malta

- There is a lack of commitment to deinstitutionalisation, with institutions being replaced by “community centres” (i.e. smaller institutions);
- All “community centres” are funded by ESI Funds.

Netherlands

- ESI Funds are not used for deinstitutionalisation, but to support employment and reintegration of the long-term unemployed (though this does not include disabled people);
- It is of concern that 60% of disabled people live at home with parents and many of them are likely to end up in institutions, if not provided with adequate support and access to housing and other services.

Portugal

- The disability strategy provides for development of community-based services, but has not been implemented yet; the medical model of disability is still prevalent, with Centres for Independent Living required to employ medical/social care professionals if they are to provide community-based services;
- Small institutions, with 12 people per home, were funded by ESI Funds in 2007 – 2013; there are concerns that this will continue in the current programming period;
- There are also concerns that funds have been spent on training Personal Assistants, who are then not employed to support disabled people;
- The Portugal 2020 programme (POISE), funded by ESI Funds, will support the National pilot project for Independent Living, which will work through the creation of Independent Living Support Centers (CAVI) – there are concerns about implementation, however; where these centres will be placed and whether they will be run by institutional care providers;
- Through the National project, app. 200 people should be supported with personal assistance in the period of 2 years, but limited to 40 hours per week;
- DPOs lack information and capacity to advocate for the use of ESI Funds for deinstitutionalisation.

Romania

- Calls under the deinstitutionalisation priority have been launched, but the projects have not been selected yet;
 - There are concerns in relation to the types of alternatives that will be created to replace large institutions – there are plans to build smaller settings, linked to a day care centre;
 - Other, related concerns, include evaluation of services (i.e. of the projects funded), and the fact that some 74,000 people have been deprived of legal capacity (i.e. are under guardianship). Therefore, they are unable to make decisions about their lives, where and with whom they will live. This includes those individuals who will ‘benefit’ from ESI funded projects.
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Slovakia

- There are concerns about delays in the implementation of National project aimed at facilitating deinstitutionalisation (which is included as a goal in both the Partnership Agreement and the Operational Programmes);
- Although Slovakia was highlighted as a good example of combining ESF and ERDF investments in the previous programming period, there are now major problems in this regard. ESF and ERDF investments are meant to be complementary, with the ESF funding “soft measures” (training and preparation of transformational plans for institution, support for staff and clients) and ERDF community-based infrastructure. However, while ERDF call was open in May 2017, the ESF National project has not started yet. As a result, there was a very low response to the ERDF call, because the potential applicants (institutions) have not been adequately prepared;
- There is resistance to the process at the regional level, because the social services are under the regional authorities; one indication of this is that the Government planned to spend 200 million EUR, whereas the regions applied for 70 mil EUR (out of which 90% are ESI Funds);
- Territorial strategies do not place an emphasis on community-based services, in contrast to the Partnership Agreement and the Operational Programmes; yet, ERDF allocations are planned according to these strategies;
- There are barriers for NGOs to access funding – co-financing was required for partners in the National project (due to the state aid rules), and the ESF Managing Authority prefers big projects. The European Commission has asked the Managing Authority to open more calls, not just those for the (large) National projects;
- There are problems caused by rules on state aid, with Slovakia lacking clear rules for providing social services as services of general interest.

Slovenia

- According to 2015 research⁴⁷ carried out by MDI – a Network on Deinstitutionalisation, there were more than 4,000 disabled people in institutions; most of them are there, because the services in the community are not available;
- There are concerns about the implementation of the deinstitutionalisation priority in the Operational Programmes. There is a plan to build 100 units (individual and in groups of 10) and to move at least 900 people out of institutions into these new units (with institutions being transformed into community-based service providers). However, there is no moratorium on the closure of institutions (with waiting lists still in place for people to enter), and there is no plan for the prevention of institutionalisation;
- There are delays in the current programming period when it comes to deinstitutionalisation. Since 2015, no calls have been launched for the implementation of pilot deinstitutionalisation projects or improving services in the community. (The list of necessary services to live independently in the community was made by users and NGOs in the 2015 research, mentioned above.);
- Concerns have been raised about the renovation of institutions using funds for improving energy efficiency of the buildings; it was also reported that new institutions for disabled people are being built from the national budget;
- In November 2017, the EEG wrote to the Managing Authority and the European Commission about ESF investment into long-stay residential institutions for children and young people with behavioural problems. These related to the use of ESF to fund the establishment of ‘centres of expertise’ within a selected number of long-stay residential institutions, without any plans for the closure of these facilities and their replacement with support services in the community.

⁴⁷ See: <http://www.za-mdi.si/files/aktivnosti/Analiza%20final.pdf> (in Slovenian, with a summary in English)

Spain

- Most concerns relate to the difficulty in accessing information on ESI Funds spending, the lack of transparency and the lack of consultation with DPOs (with a strong lobby by the large charities);
- Lack of communication at regional/local level between different departments was also reported, as was the lack of assessment of individual needs.

United Kingdom

- Although there is no deinstitutionalisation priority in the Operational Programmes, it was reported that the country was experiencing a move backwards towards institutionalisation (due to, among other, the closure of the Independent Living Fund and the decrease in the local authorities' budgets);
 - Concerns were expressed about the effect of Brexit on the right to independent living, with many personal assistants, carers and health care staff coming from other parts of the EU.
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Annex B:

List of organisations which took part in the EU Funds for Our Rights regional events

Country	Organisation(s)
Belgium	EVA asbl
Bulgaria	Centre for Independent Living Sofia
Croatia	Kuca ljudskih prava (Human Rights House), Association for Self-Advocacy, SOLIDARNA – Foundation for human rights and solidarity
Czech Republic	Quip: Quality in Practice
Estonia	Challenge Your Senses
Germany	Verein zur sozialen und beruflichen Integration e.V.
Greece	i-living, Institute of Child Health – Department of Mental Health and Social Welfare
Hungary	Hungarian Civil Liberties Union (TASZ)
Latvia	ZELDA
Lithuania	Lithuanian National Federation of Users of Psychiatry, Vilnius University, Lithuanian Disability Forum, Mental Health Perspectives, National Network on Poverty Reduction, Viltis, SOS Children's Villages, Women's Information Centre, Giedra, Children's Confederation
Malta	Federation of Organisations Persons with Disability
Netherlands	Coalition for Inclusion
Portugal	Centro de Vida Independente (Centre for Independent Living)
Romania	Consiliul de Monitorizare, Mental Disability Advocacy Centre, Concordia, PRO ACT Support, World Vision, In Dialog, Centre for Legal Resources, European network of ex/Users and Survivors of Psychiatry
Slovakia	SOCIA Foundation
Slovenia	YHD – Drustvo za teorijo in kulturo hendikepa (Association for Theory and Culture of Handicap), Faculty for Social Work, University of Ljubljana
Spain	FICE – International Federation of Educative Communities
UK	University of Leeds
EU level	Autism Europe, European Association of Service Providers for Persons with Disabilities (EASPD), Inclusion Europe, Human Rights Watch, European Disability Forum (EDF), Eurochild, Lumos/Structural Funds Watch -Community Living for Europe; SOS Children's Villages international

Annex C: Definitions

Independent Living⁴⁸

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 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/or 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.

Independent living arrangements⁴⁹

Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not “just” about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family.

Personal Assistance

Personal Assistance is 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

48 Adopted in November 2012 by the ENIL board. The definition of independent living was adopted by the European Disability Forum in March 2016.

49 This definition comes from the General Comment No. 5 on Article 19 CRPD, para. 16(c).

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.

Deinstitutionalisation

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalisation 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 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.

Being included in the community⁵⁰

The right to be included in the community relates to the principle of full and effective inclusion and participation in society as enshrined in, among others, article 3 (c) of the Convention. It includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them to be fully included and participate in all spheres of social life. These services can relate, among others, to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media. The right also includes having access to all measures and events of political and cultural life in the community, among others, public meetings, sports events, cultural and religious festivals and any other activity in which the person with disability wishes to participate.

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, 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. 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, the need for special transport because mainstream transport is inaccessible and so on. In many cases, group homes do not support independent living. Where they are provided, they must form part of a range of community-based services that offer genuine, adequately funded independent living options.

⁵⁰ This definition comes from the General Comment No. 5 on Article 19 CRPD, para. 16(b).

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL has Participatory Status with the Council of Europe, a Consultative Status with ECOSOC, is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform, and on the Advisory Council on Youth at the Council of Europe.

About the EU Funds for Our Rights Campaign

On 8 November 2016, ENIL launched a campaign on the use of European Structural and Investment Funds ('Structural Funds') in the European Union (EU) Member States. The aim of the *EU Funds for Our Rights Campaign* is to encourage the European Commission and the Member States to improve the monitoring and complaints system, in order to ensure that Structural Funds are used to support the rights of disabled people, rather than restrict them. Specifically, the *EU Funds for Our Rights Campaign* is focusing on the role of Structural Funds in supporting the right to live independently and being included in the community, set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). The campaign is supported by the Open Society Foundations – Public Health Program.



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